DOCUMENT RESUME

ED 259 498 EC 180 234

AUTHOR	Agosta, J. M., Ed.; Bradley, V. J., Ed.
TITLE	Family Care for Persons with Developmental Disabilities: A Growing Commitment.
INSTITUTION	Human Services Research Inst., Boston, MA.; National Association of State Mental Retardation Program Directors, Alexandria, VA.
SPONS AGENCY	Administration on Developmental Disabilities (DHHS), Washington, D.C.; Office of the Assistant Secretary for Planning and Evaluation (DHHS), Washington, D.C.
PUB DATE	20 May 85
GRANT	DHHS-90DD0049-01; DHHS-123A-A3
NOTE	306p.
AVAILABLE FROM	Human Services Research Institute, 120 Milk St., 8th Floor, Boston, MA 02109 ($19.00).
PUB TYPE	Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01/PC13 Plus Postage.
DESCRIPTORS	Delivery Systems; *Developmental Disabilities; Elementary Secondary Education; *Family Programs; Family Role; *Financial Support; National Surveys; *Public Policy

ABSTRACT

The report presents findings from a study of family-based care for persons with developmental disabilities. The first of four parts introduces the problems of family-based care and presents perspectives of parents and of persons with developmental disabilities. Part 2, on responding to the needs of families, includes a review of historical and contemporary responses to disability, a discussion of the development of family support programs, and a summary of a national survey of existing family support programs (with information on the role of the family, means of service administration, permissible services, and the potential for consolidating resources). Part 3 presents six sections on the following contemporary service directions: policy options for family support services, families and future financial planning, tax policy to support families, private sector resources to support families, evaluation of family support programs, and family support options. The final part presents 13 recommendations for change in family based care and social policy. Five persons contributed concept papers to this report: Paul Castellani, "Policy Options for Family Support Services"; Addie Comegys, "A Parent's Perspective"; Susan Lamb, "The Perspective of a Person with Disabilities"; Robert Perlman, "Family Support Options: A Policy Perspective"; and Colleen Wieck, "The Development of Family Support Programs." (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED259498

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

- Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A GROWING COMMITMENT

May 20, 1985

EC 172 234

"PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY
John M
Agosta
TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

This project was supported by the U.S. Department of Health and Human Services primarily through the Office of the Assistant Secretary for Planning and Evaluation (Grant Number: 123A-A3). In addition, because the goals of this project were complemented by those pursued as part of another project, it should be noted that the Administration on Developmental Disabilities also helped to support portions of this effort (ADD Grant Number: 90DD0049/01).

The views expressed herein are soley those of the authors and should not be construed as representing the opinions or policy of any agency of the United States Government.

Project Officer:

Jerry Silverman
ASPE/DHHS
Hubert H. Humphrey Building (room 447F)
200 Independence Avenue, SW
Washington, DC 20201

FAMILY CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A GROWING COMMITMENT

PROJECT STAFF

HUMAN SERVICES RESEARCH INSTITUTE

phone: 617-542-1812

VALERIE BRADLEY (PROJECT DIRECTOR)
JOHN AGOSTA

NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS

phone: 703-683-4202

ROBERT GETTINGS
BERYL FEINBERG
DEBBIE JENNINGS
RUTH KATZ

PROJECT STAFF ASSISTANTS

SAM AUSTIN
KAREN HARTFIELD
PAUL NURCZYNSKI
ANNE RUGG

CONCEPT PAPER AUTHORS

PAUL CASTELLANI	POLICY OPTIONS FOR FAMILY SUPPORT SERVICES
ADDIE COMEGYS	A PARENT'S PERSPECTIVE
SUSAN LAMB	THE PERSPECTIVE OF A PERSON WITH DISABILITIES
ROBERT PERLMAN	FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE
COLLEEN WIECK	THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS

THE RECOMMENDED CITATION FOR THIS ENTIRE PUBLICATION IS AS FOLLOWS:

Agosta, J.M. & Bradley, V.J. (Eds.)(1985) Family care for persons with developmental disabilities: A growing commitment. Boston, MA: Human Services Research Institute.

ADDITIONAL COPIES OF THIS PUBLICATION MAY BE OBTAINED, POSTPAID AT $19 PER COPY, CHECK PAYABLE TO HUMAN SERVICES RESEARCH INSTITUTE, FROM

HUMAN SERVICES RESEARCH INSTITUTE
FAMILY CARE REPORT
120 MILK STREET (8TH FLOOR)
BOSTON, MA 02109

ACKNOWLEDGEMENTS

The authors recognize and appreciate the significant contributions made by many throughout the course of this project. Thanks are due those who responded to our requests for information on family support programs operating around the country, the conference participants who sharpened and broadened our understanding of the many issues involved with supporting families, and members of the National Advisory Committee who reviewed initial project materials.

Special thanks are extended to Gunnar Dywbad, Ph.D., Dorothy Lipski, Ph.D., and Kris Slentz, Ph.D., for the guidance they provided regarding various aspects of the final report. In addition, we would like to thank staff in the office of the Assistant Secretary for Program Evaluation, and especially Jerry Silverman, who reviewed drafts of our work and provided us direction.

This report is dedicated to all those families who provide or have ever provided home care to persons with developmental disabilities.

TABLE OF CONTENTS

PREFACE iv

OVERVIEW..1

PART I: THE FAMILY..5

THE FAMILY AND ITS NEEDS....................................6

The Family and Family-Based Care............................6
Prevalence of Family-Based Care.............................11
Coping with Disability in Families..........................11
Families and the Presence of a Member with a Developmental Disability..........12
Needs of a Person with Developmental Disabilities...........14
Overall Needs of Families...................................15

A PARENT'S PERSPECTIVE......................................18

The Advent of a Disability in a Family......................19
Implications for Families Providing Habilitative Care.......22
Services that Families Require..............................22
Family Well-Being...28
Recommendations for Improving Support Services..............30

THE PERSPECTIVE OF A PERSON WITH DISABILITIES...............34

Self-Awareness, Integrity and Disability....................35
The Ultimate Objective: Independence........................39
Some Crucial Concerns.......................................46
Conclusion..54

PART II: RESPONDING TO THE NEEDS OF FAMILIES................55

HISTORICAL AND CONTEMPOARY RESPONSES TO DISABILITY..........56

Conflict in Roles over Time.................................57
Present Barriers to Increased Support for Families..........59
Factors Spurring Increased Demand for Family Support........66
The Current Challenge.......................................68

THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS..................70

Defining Human Problems in Terms of Professional Solutions..70
Difficulty of Obtaining Assistance in the Home..............74
Relative Ease of Obtaining Care with an Out-of-Home Placement..........77

- Equity and Effectiveness of Family Support Programs.....79
- Advantages of Family Care.....81
- Economic Inefficiency of Out-of-Home Placement.....82
- Evaluation of Family Subsidy Programs.....84
- The Trend Toward Professionalism.....89
- Improving Family Support Programs.....89

STATEWIDE FAMILY SUPPORT PROGRAMS: NATIONAL SURVEY RESULTS.....94

- Method.....94
- Results.....96
- Discussion.....106
  - The Role of Family.....107
  - Program Eligibility.....108
  - Means of Service Administration.....108
  - Permissible Services.....111
  - Consolidating Resources.....111

PART III: CONTEMPOARY SERVICE DIRECTIONS.....113

POLICY OPTIONS FOR FAMILY SUPPORT SERVICES.....114

- What Are Family Support Services?.....115
  - Policy Issues.....115
  - Current State Family Support Services.....116
  - Policy Options and Implications.....118
- Who Should Receive Family Support Services?.....121
  - Policy Issues.....121
  - Eligibility Criteria in Current State Programs.....126
  - Policiy Options for Eligibility Criteria.....126
- How Should We Deliver Family Support Services?.....128
  - Policy Issues and Current Options.....128
  - Summary.....136
- Funding Family Support Services.....137
  - Policy Issues.....137
  - Current Sources.....138
  - Sources for Additional Funds.....139
  - Summary.....145
- Conclusion.....147

FAMILIES AND FUTURE FINANCIAL PLANNING.....149

- Method.....152
- Results.....153
- Discussion.....158
  - What's the Best Way to Establish a Financial Planning Program?.....158
  - What Role Should Government Play in Assuring Quality?.....160
  - What Place Does Financial Planning Have in the Service Continuum?.....162

USING TAX POLICY IN SUPPORT OF FAMILIES WHO HAVE A MEMBER WITH DEVELOPMENTAL DISABILITIES................165

Potential Tax Policy Options........................165
Present Federal Level Tax Policy...................167
State Level Tax Policy...............................176
Relevant Issues......................................179

USING PRIVATE SECTOR RESOURCES TO SUPPORT FAMILIES WHO HAVE A MEMBER WITH DEVELOPMENTAL DIABILITIES.........184

Family Care and the For-Profit Sector..............184
Employer Centered Independent Initiatives..........196
Relevant Issues Regarding Private Sector...........197

EVALUATING FAMILY SUPPORT PROGARMS.....................201

Types of Evauation Needed...........................201
Difficulities in Conducting Program Evaluations....205
Review of the State-of-the-Art.....................210
Conclusion...218

FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE..........220

Factors for Against Family-Based Care..............222
Gaps in Current Knowledge...........................227
1270 Families Engaged in Family Based Care.........228
Possible Directions for Family Based Care Policy...236
Conclusion...247

PART IV: RECOMMENDATIONS................................251

FAMILY BASED CARE AND SOCIAL POLICY: RECOMMENDATIONS FOR CHANGE..252

COMPOSITE BIBLIOGRAPHY.................................264

APPENDIX A: LIST OF CONFERENCE PARTICIPANTS...............286

APPENDIX B: DIRECTORY OF 22 FAMILY SUPPORT PROGRAMS.......289

APPENDIX C: DIRECTORY OF 11 FINANCIAL PLANNING AGENCIES...292

PREFACE

In the past two decades, we have watched as an increasing number of disavantaged and disenfranchised groups moved to the forefront to assert their rights to participate as full members of the society. The move was begun by black civil rights groups but later grew to encompass women, and more recently, persons with disabilities. The common aspiration of all of these movements is a desire to control one's own destiny and to gain the power to affect one's immediate circumstances. This spirit is also present today in attempts to move the control of human services programs closer to local communities and in the explosion of self-help and self-advocacy groups around the country. It is within this context that the following report on the enhancement of the capacity of families to care for developmentally disabled family members should be viewed.

Historically, the families of persons with developmental disabilities have been viewed as more of an impediment to the habilititation of their family member than as a potential care-giving resource. The author of a relatively recent article in a reputable academic journal epitomized the condescending attitude that some professionals have traditionally reserved for parents: "We cannot assume that families have the intelligence, values, education, motivation or interest to enable them as a unit to proceed as a cooperative member in decision-making." Instead of assisting families to understand the nature of their child's needs and the steps they might take to help them [illegible]ny professionals counselled out-of-home placement and forgetting.

Today, the families of persons with developmental disabilities are asking that their role as caretaker be acknowledged and are requesting the information and support necessary to provide such assistance. At the same time, more and more families are coping with increasingly disabled infants whose survival is made possible by advances in neonatal care. These families are faced with enormous responsibilities and family stresses. The material in the ensuing report is meant to assist in the "empowerment" of families and to suggest concrete ways in which both the public and private sectors can facilitate the maintenance of the family unit while improving of the life chances of the family member with developmental disabilities.

The preparation of the following report was a joint venture between the Human Services Research Institute and the National Association of State Mental Retardation Programs (NASMRPD). The support of the staff of NASMRPD -- Robert Gettings, Deborah Jennings, Beryl Feinberg, and Ruth Katz -- throughout the project was deeply appreciated.

Valerie J. Bradley
President
Human Services Research
Institute

OVERVIEW

Parents of sons or daughters with developmental disabilities face a variety of dilemmas and choices regarding the long term needs of their offspring. Traditionally, such families have been accorded few supports and have often been encouraged to seek residential placement for their child with disabilities away from the family home. Policy initiatives, however, have focused increasingly on establishing statewide programs of systematic support to care-giving families.

Pursuant to a grant from the Department of Health and Human Services, the Human Services Research Institute (HSRI) cooperated with the National Association of State Mental Retardation Program Directors (NASMRPD) to acquire an improved understanding of this movement. To achieve this goal, the following three objectives were set:

- To identify new and creative ways of involving families in caring for their relatives with developmental disabilities and to determine the barriers to growth and acceptance of these new approaches;
- To identify new approaches for encouraging families to plan financially for the future of their relatives with developmental disabilities; and
- To examine the fiscal incentives and disincentives that influence parental choices regarding the placement of family members with developmental disabilities and to identify innovative ways of countering incentives that favor out-of-home placement.

These objectives were achieved through a variety of activities, including:

- Solicitation of information from knowledgeable officials in 50 states. This survey provided information on the status and character of family support programs around the country.

- Preparation of a literature review that reflects the state-of-the-art in family support theory and practice. Information was collected through a search of library materials and by soliciting information in the publications of 20 relevant organizations.
- Development of five concept papers related to family-based care. The first paper presents an overview of the goals and purposes of family support services. The second presents a parent's perspective on the topic while the third offers the perspective of a person with disabilities. The fourth paper discusses current options for family support policy. The final paper examines future policy directions.
- Conduct of a working conference on family-based care. This conference was attended by approximately 40 persons representing a wide range of interests, perspectives, and knowledge.

The report that follows addresses several significant issues related to the provision of family-based care to persons with developmental disabilities. In addition to this report, there is also an executive summary that highlights many of the project's key findings, and an edited compilation of the proceedings of HSRI's working conference on family support.

In addition, the appendices to this report provide much useful information. Appendix A, presents a list of persons participating in the HSRI family support conference. Appendix B provides a directory of 22 statewide family support initiatives. Finally, a directory of 11 organizations that offer parents financial planning services to help assure the future well being of their sons and daughters with disabilities is provided in Appendix C.

The activities of this project have been directed at learning more about the needs of families who provide care to persons with developmental disabilities and at exploring what can be done to enhance their efforts. Our findings suggest that recent calls to "support not supplant" family efforts have not gone unheeded in light of the number of states that have initiated extensive family support programs. However, there is still more to be done and we hope that this report will spur the further development of programs for persons with developmental disabilities and their families.

This report's major chapters are as follows:

PART I: THE FAMILY

I. THE FAMILY AND ITS NEEDS:

This chapter presents key definitions of terms along with information on the prevalence of family-based care, the problems families have with coping with the advent of disability, and their overall service needs.

II. A PARENT'S PERSPECTIVE:

This portion of the report is written by a parent of a daughter with developmental disabilities and includes thoughtful insights regarding family needs.

III. THE PERSPECTIVE OF A PERSON WITH DEVELOPMENTAL DISABILITIES:

This section is written by a person with disabilities and provides information regarding the needs of the family member with a disability.

PART II: RESPONDING TO THE NEEDS OF FAMILIES

I. HISTORICAL AND CONTEMPORARY RESPONSES TO DISABILITY:

This chapter describes the tension between society's responsibility to care for persons with disabilities on the one hand, and the family's responsibility on the other. It also includes a discussion of present barriers to increased public support for families, factors spurring increased demand for family support, and the challenges to professionals in developing such services.

II. THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS:

This portion of the report, written by the director of a state developmental disabilities council, offers information regarding what can be done on a policy level to support families.

III. STATEWIDE FAMILY SUPPORT PROGRAMS: NATIONAL SURVEY RESULTS:

In this chapter results of a national survey of existing family support programs are presented.

PART III: CONTEMPORARY SERVICE DIRECTIONS

I. POLICY OPTIONS FOR FAMILY SUPPORT SERVICES:

This chapter, written by a state level program planner, reviews the numerous factors that program planners must consider when designing state-wide programs of family support.

II. FAMILIES AND FUTURE FINANCIAL PLANNING: NATIONAL SURVEY RESULTS

This section includes the results of a national survey of programs that offer future financial planning services to families.

III. USING TAX POLICY TO SUPPORT FAMILIES:

The potential for encouraging family-based care by modifying existing tax policy is discussed in this chapter.

IV. USING PRIVATE SECTOR RESOURCES TO SUPPORT FAMILIES:

Utilizing the resources of businesses and industry to support family efforts is highlighted in this section.

V. EVALUATING FAMILY SUPPORT PROGRAMS:

This chapter discusses the importance of evaluating family support initiatives, and presents information regarding the difficulities with such evaluation and the results of a sample of completed evaluations.

VI. FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE:

This chapter, written by a family policy analyst, places the concept of family support in the context of policy development over time and suggests what must be done to encourage family-based care in the long term.

PART IV: RECOMMENDATIONS

Based on project findings, numerous recommendations are offered to modify existing social policy, and to improve family support efforts through the conduct of evaluations.

PART I: THE FAMILY

Chapter 1: The Family and Its Needs

Chapter 2: A Parent's Perspective

Chapter 3: The Perspective of a Person with Developmental Disabilities

THE FAMILY AND ITS NEEDS

During the past twenty years, the norms and mores affecting American family life have undergone rapid changes. Parents of children with developmental disabilities have also endured these changes and additionally have experienced significant shifts in the way society responds to persons with developmental disabilities. Until recently parents of such children were afforded only two residential service options: parents could forego traditional parental functions by placing their child in an institution or they could provide care at home with little or no external support. A third option, however, is slowly evolving. This option is symbolized by the rapid growth of community-based services that increasingly serve as an alternative to institutionalization. Among these services are those that provide assistance to families who choose to maintain persons with developmental disabilities within the family. Prior to designing or implementing family assistance programs, however, the needs of families must be clearly understood.

The Family and Family-Based Care

Any discussion of care provided by families to members with developmental disabilities must begin with definitions of three fundamental terms: family, developmental disability, and family-based care.

- Family. In the simplest sense, "family" can be defined in terms of its composition. As such, the notion of "family" is viewed traditionally as a group of two or more persons who live together and who are related by blood, marriage or adoption. In her chapter

(Part II, Chapter 2), however, Colleen Wieck reminds us that today's patterns of social bonding require a much broader conception and that the term "family" must encompass a wider variety of potential groups. Reflecting this trend, the U.S. Census Bureau has adopted the term "household" as a means of tracking the composition and characteristics of persons living together and functioning as a family unit.

Though understanding the range of possible family groups is useful for developing family support policy, families should also be understood in terms of the role each member plays and the interaction between members. To help achieve this end, Turnbull, Brotherson & Summers (1985) developed "The Family System Model." Figure 1 displays the primary components of their model and suggests that the family may be thought of in terms of four specific subsystems and three types of family characteristics. The four family subsystems are: 1) spousal interactions, 2) parent-child interactions, 3) sibling-sibling interactions, and 4) family interactions with extended family members and community or professional support networks. The exact composition and functioning of each subsystem varies by family. For instance, some families have a single parent, while in others the child with disabilities has no siblings.

The three types of family characteristics that affect family interactions are displayed in greater detail in Figure 2. The first pertains to family structure. Family structure can vary in several ways including: 1) size, composition, and the roles each family member play in the family, 2) cultural style (i.e., ethnic background, race, religious affiliation), 3) ideological style

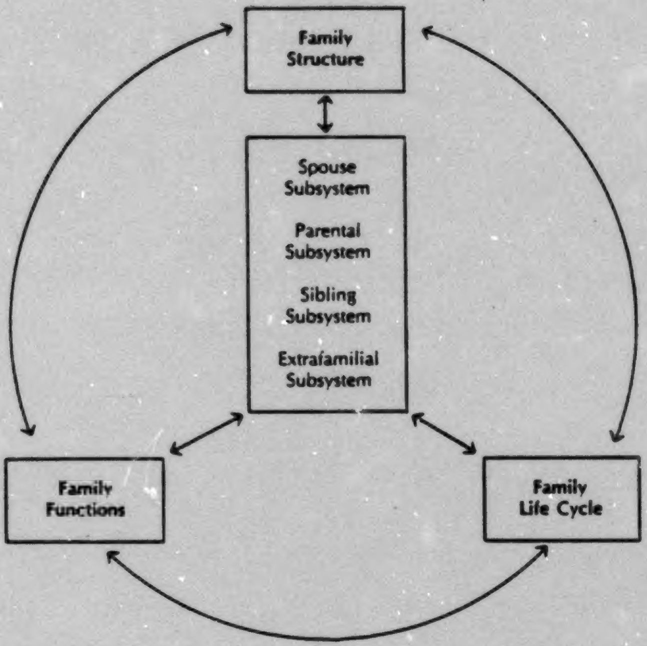

Family Structure
Spouse Subsystem
Parental Subsystem
Sibling Subsystem
Extrafamilial Subsystem
Family Functions
Family Life Cycle

Figure 1: The Family Systems Model*

*Source: Turnbull et al., 1985

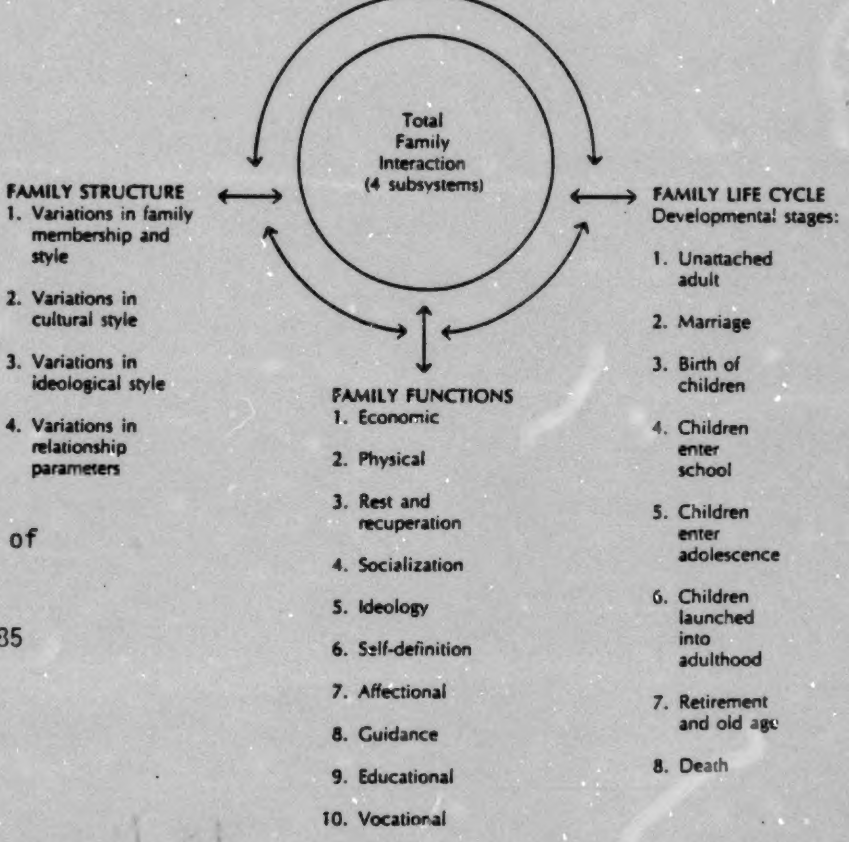

Total Family Interaction (4 subsystems)
FAMILY STRUCTURE
1. Variations in family membership and style
2. Variations in cultural style
3. Variations in ideological style
4. Variations in relationship parameters
FAMILY LIFE CYCLE
Developmental stages:
1. Unattached adult
2. Marriage
3. Birth of children
4. Children enter school
5. Children enter adolescence
6. Children launched into adulthood
7. Retirement and old age
8. Death
FAMILY FUNCTIONS
1. Economic
2. Physical
3. Rest and recuperation
4. Socialization
5. Ideology
6. Self-definition
7. Affectional
8. Guidance
9. Educational
10. Vocational

Figure 2: Three Perspectives of Family Dynamics*

Source: Turnbull et al., 1985

(i.e., the family's beliefs about what is important or not important in familial and community life), and 4) interpersonal dynamics that dictate authority and communication patterns.

The second general category pertains to family functions. This refers to crucial areas of family life where families have mutually beneficial responsibilities. For example, each family member has a need for affection and can expect other family members to help satisfy this need. In turn, the individual family member must show affection for other family members.

The third category is family life cycle and is divided into two areas: developmental stages and stage transitions. These concepts reflect the process of evolution and change that families experience as they proceed through various life stages. A developmental stage is a specific milestone in the life span of a family (e.g., marriage, birth of children, retirement). A stage transition is what happens immediately before and after each development stage (i.e., feeling stress, and coping with the effects of change).

A complete presentation and analysis of this model of family dynamics is beyond the scope of this report. Turnbull et al. (1985), however, provide evidence that the successful integration of a person with disabilities into the family will in great part depend on the nature of various interactions among family members and on a variety of other factors that influence family behavior. Consequently, researchers are challenged to determine how these factors act alone and together to affect a family's caregiving capacity. Moreover, policymakers are challenged to make use of this knowledge to improve family support practices.

o Developmental Disability. For our purposes, the definition of developmental disability is taken from the Comprehensive Services and Developmental Disabilities Amendments of 1978 (P.L. 95-602) and is as follows: "the term 'developmental disability' means a severe chronic disability of a person which

a) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

b) Is manifested before the person(s) attains age 22;

c) Is likely to continue indefinitely;

d) Results in substantial functional limitations in three or more of the following areas of life activity;

   1. Self Care
   2. Receptive-expressive language
   3. Learning
   4. Mobility
   5. Self-direction
   6. Capacity for independent living; and
   7. Economic self-sufficiency; and

e) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are individually planned and coordinated." [Sec. 102(7)]

- Family-Based Care. Family-based care is provided when a person with developmental disabilities lives with his/her natural family (i.e., parents, siblings, other relatives). Expanding this basic definition, Horejsi (1979) notes two types of family-based care: habilitative and ordinary. Habilitative family care occurs primarily in the family home and is carried out by family members who assume major responsibility for ordinary parenting duties and some responsibility for providing more therapeutic or habilitative care. This type of care is planned systematically and is augmented by family assistance services to strengthen the family and integrate the person with developmental disabilities into the family unit (Bryce, 1979; Horejsi, 1979). In contrast, ordinary family-based care refers to situations where persons with developmental disabilities remain at home, receive food, shelter and the concern of family members, but do not receive structured habilitative care and services (Horesjsi, 1979).

Prevalence of Family-Based Care

Bruininks (1979) observes that nearly everyone in society belongs to a family unit and that most persons live within such units, especially from birth to early adulthood. Present evidence suggests that these same observations hold true for persons with developmental disabilities.

Most estimates of the number of non-institutionalized persons with developmental disabilities, range from just 2.5 million (Boggs and Henney, 1981) to 3.2 million (Bruininks, 1983). Further, Hauber, Bruininks, Hill, Kakin and White (1982), show that only 243,669 persons with developmental disabilities live in out-of-home settings (i.e., institutions, psychiatric hospitals, nursing homes, foster homes, and community-based facilities).

Based on these considerations, it seems safe to assume that relatively few persons with developmental disabilities live away from their natural family during the developmental stages of their lives. Rather, the great majority stay at home because their families choose to provide family-based care (Perlman, 1983; Maroney, 1981; Bruininks, 1979).

Coping with Disability in Families

Until recently, little attention was paid to the needs of families who provide long-term care to their members with developmental disabilities. Recent efforts, however, have resulted in a growing literature on the topic. Though the absence of a comprehensive national data base regarding the number and demographic characteristics of caregiving families remains a concern of policy planners, much has been learned about the effects of disability on a family and the needs of persons with disabilities. Such information can be used to gain an understanding of what support families require to provide effective family-based care.

Families and the Presence of a Member with a Developmental Disability

The presence of a person with developmental disabilities in the home can present the family with a variety of extraordinary challenges. There are, however, inconsistent and contradictory findings regarding the nature and severity of such challenges. In general, available research suggests that any problems individual families experience are related to multiple factors including the seriousness of the family member's disability, the presence of maladaptive behavior, family characteristics, the family's emotional status, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services (Crnic, Friedrich & Greenberg, 1983; Nihira, Mink & Meyers, 1980; Mink, Meyers & Nihira, 1984). As a result, Moroney (1983) notes that though not all families experience extraordinary problems, all are "at risk" because they are more likely to have difficulties than families without members with disabilities.

For many families the initial recognition that a severe disability exists persents an immediate crisis that evolves into a life crisis. Several of the problems families can experience include:

- Adverse reactions to the discovery that a family member has a developmental disability including a sense of shock or numbness, denial, grief, shame, guilt and depression (Fortier & Wanlass, 1984; English & Olson, 1978);

- Chronic stress (Wikler, 1983; Kazak & Marvin, 1984; Beckman-Bell, 1981);
- Social isolation resulting from perceived negative attitudes and/or rejection by kin or neighbors (Gottlieb, 1975; English & Olson, 1978);
- Financial costs or lost opportunities such as jobs, advancement, and education (Dunlap, 1976; Turnbull, et al., 1985; Gliedman & Roth, 1980);
- Extraordinary time demands involved in providing personal care to the family member with disabilities (e.g., feeding, washing, dressing) (Bayley, 1973; Dybwad, 1966; Apolloni & Triest, 1983);
- Difficulty with physical management (e.g., ambulation, lifting, carrying) and in handling socially disruptive or maladaptive behavior (Justice et al., 1971; Bayley, 1973; Tausig, 1985; McAndrew, 1976);
- Difficulty in undertaking normal family routines such as shopping and house cleaning or in finding ample opportunity for recreation (Bayley, 1973; Lonsdale, 1978; McAndrew, 1976); and
- Lack of the skills needed to cope with the potential medical emergencies and/or to teach necessary adaptive skills (see English, 1984).

Another problem that families may face is marital discord. A prevailing notion in the field is that the ongoing burden of long-term care places great strain on marriages and results in divorce more frequently than is apparent in the general population. Review of the literature, however, does not readily support this claim (Perlman & Giele, 1983; Longo & Bond, 1984). The confusion in research findings suggests that marital satisfaction may be dependent on numerous other factors besides the presence of a son or daughter with disabilities. Though it seems likely that the demands of long-term care could affect some marriages, additional research is needed to probe more deeply into the effect that the presence of a son or daughter with disabilities has on the relationship between husband and wife.

Needs of Persons with Developmental Disabilities

As defined in greater detail earlier, persons with developmental disabilities require special care due to physical and/or mental impairments that occur before age 22, and that result in severe functional limitations in a variety of life skills. This definition is stated in such broad terms that it encompasses a variety of handicapping conditions including, but not limited to, mental retardation, cerebral palsy, epilepsy, and autism. The advantage of using a definition based on functioning level is that it groups together a variety of persons requiring comparable long-term care and results in fewer persons "falling through the cracks" of rigid service eligibility criteria. The primary disadvantage is that it is difficult to compile precise demographic information on the entire population with developmental disabilities.

Review of available information, however, suggests that:

- Mental retardation is the primary disability listed for the great majority of persons with developmental disabilities (Lubin, Jacobson, & Kiley, 1982);
- Persons with developmental disabilities have severe functional limitations due to inadequate skills, maladaptive behavior, or extraordinary medical needs; and
- Persons with developmental disabilities often possess multiple handicaps (Moroney, 1983; Lubin *et al*., 1982; Lea, Reed & Hansen, 1978).

Given these considerations, persons with developmental disabilities can have extraordinary needs pertaining to:

- Health status: Several types of disabling conditions require frequent monitoring of biological functions. Moreover, they require that caretakers be knowledgeable about the means for coping with medical emergencies.
- Health maintenance: Many health professionals are not trained to cope with extraordinary health needs of persons with developmental disabilities. Consequently, many routine health maintenance tasks are greatly complicated. A child with a severe reverse tongue thrust and little voluntary muscle control may need to see a special dentist. Likewise, a person

with down syndrome and a chronic heart condition may need to see a doctor who is familiar with such health conditions.

- Adaptive skills: Persons with mental retardation have problems with learning. Additionally, persons with developmental disabilities and normal intelligence may acquire skills at a reduced rate because of their physical condition. Regardless of the the nature of the problem, persons with developmental disabilities generally require increased opportunities for learning and can benefit greatly from specialized instructional assistance throughout life in a variety of settings (e.g., residential, vocational).

- Socio-behavioral skills: Among persons with developmental disabilities, the inability to learn and grasp concepts quickly, diminished ability to communicate or the frustrations of being disabled can result in maladaptive behavior. Eliminating such behavior can require extraordinary effort from parents and may necessitate consultation with a behavioral specialist. In addition, even if such needs do not evolve, persons with disabilities may require counseling to promote development of a healthy self concept.

- Specialized needs: Many persons with developmental disabilities may require specialized treatment such as speech or physical therapy. In addition, they may require a variety of personal or environmental prosthetics (e.g., adaptations to the home, braces, special wheelchairs, etc.).

In addition to the several needs described above, two other factors must be considered. First, the needs of persons with developmental disabilities will change over time as the individual progresses from one developmental plateau to the next (Konanc & Warren, 1984; Suelzle & Kennan, 1981). Second, as parents grow older their capacity to provide care changes. Moreover, in addition to meeting daily life requirements, parents must eventually give thought to how the needs of their family member with disabilities can be appropriately met after they can no longer provide direct care.

Overall Needs of Families

The above review suggests that in addition to the direct care services required by the family member with disabilities the family also needs support services to enhance its caregiving capacity.

Participants at HSRI's working conference on family support noted the following problems with the way such services are currently provided.

- Lack of individualization of services received. Because family situations are unique, services must be flexible enough to accommodate each family's individual needs. Existing family support services, however, are often designed with an insufficient capacity for such flexibility, resulting in an unsatisfactory match between services and family needs;
- Insufficient control over services received. When available support services do not match family service needs, families often have little leverage to modify the services they are offered;
- Inadequate information regarding the present and future needs of the family member with disabilities as well as the implications these needs have for family care providers. Such information also includes systematic instruction for family members regarding contemporary habilitative practices. The need for such information begins at the time of birth of the person with disabilities and continues throughout his/her life;
- Shortage of time to care for the person with disabilities, perform normal household routines, undertake productive activities such as attending school or working, and cope with other aspects of one's personal and familial life;
- Insufficient number and range of direct services for the person with disabilities. For persons with disabilities of school age this often includes the availability of habilitative activities during evenings and/or weekends. For adults with disabilities this can involve a need for daily vocational instruction, alternative community living arrangements, a variety of age-appropriate social and recreational activities, and suitable transportation services to enhance the accessibility of various community resources;
- Lack of instrumental and environmental supports. These supports include proper adaptive equipment for the person with disabilities as well as the provision of a living environment that is barrier free for both the person with disabilities and the family caretakers;
- Inadequate specialized health care to meet extraordinary needs regarding medical and/or dental care;
- Needs for a support network for and run by parents to provide informal support, share information, and overcome the social isolation many families experience; and
- Insufficient means to ensure the future well-being of the person with disabilities. This issue pertains primarily to guardianship and financial planning.

These problem areas are not and cannot be ranked in importance. Each family has a unique cluster of needs and would critique the availability and quality of services differently depending on their circumstances. In fact, many families may have problems that do not appear on the above list.

This list, however, suggests that though families are willing to provide long-term care to their members with disabilities, they need additional supports that are tailored to their unique circumstances. The challenge before us, then, is to translate this need into an effective system of supports that recognizes the therapeutic as well as human needs of families and of persons with developmental disabilities.

A PARENT'S PERSPECTIVE

By

Addie Comegys

With both support from her husband and interruptions from Kate!

Every family is different from the next, whether it includes a person with handicaps or not. But families with a member having a developmental disability share a number of goals and concerns.

We all have problems of one kind or another. That is life, a challenge to be sure. But, persons with developmental disabilities, in addition, eventually have to prove that they can contribute to society in both competitive productivity and in winning ways. To achieve this they need the supportive consistency and sustenance of their own flesh and blood from birth through death. Society must, and can, increase its desire and capacity for assimilating this population. But it must move more quickly and supportively in the immediate future then it has in the past.

I would like to see the end of placements in nursing homes or institutions for developmentally disabled individuals needing long term total care. Instead, I would like to see each person with a disability able to be cared for in their own home, just as our great great grandparents cared for their elderly family members.

Those of us who participated in the HSRI conference can provide some creative and corrective momentum by addressing accurately the genuine needs of all types of households, present and future, that are actively caring for, or considering caring for, developmentally disabled members.

We know that there are many types of families with varying levels of income trying to provide that quality care at home. Mother and father. Single parent. Working parent(s). Foster and adoptive parents. Siblings. Family friends. Extended families. Additionally, we know that the range of disabilities involved requires care that stretches from little to total care. And that range of involvement needs to be encouraged and expanded.

The purpose of this paper is to elaborate on several issues that confront parents who choose to care for their disabled child at home. Moreover, based on such discussion, recommendations are offered with regard to how family support services could be improved.

The Advent of Disability in a Family

We have friends who adopted a "normal" baby only to learn later that the baby had severe total care disabilities. That child, now twelve, has been centered and anchored in his family. But his working mother could not have done it without help from her mother who periodically comes from abroad. Incidentally, our friends have had two children naturally since they adopted.

Consider another friend whose Siamese twins were separated soon after birth, leaving one very physically dependent. She was given a death sentence of four years. Now she is fourteen and is communicating with an Apple Computer at school. Communication training began with the loan of a Zygo machine from her school system. Now her parents are faced with the expense of a home computer and a van for her special chair.

Different kinds of help are needed today. When you learn that your child has a handicap, you deny it. Then you become angry, often directing your (natural) anger towards the doctors who (usually) informed you. Family members often progress through emotional stages similar to those experienced in response to a death in the family.

Let me tell you about our own experiences with our second daughter, Kate. It was only thirteen years ago in a hospital office in our nation's capital, that my husband and I were advised by medical personnel to institutionalize our daughter who was approximately eighteen months old. Kate, we were told, was multiply handicapped. She had cerebral palsy. She was very retarded, and so, the doctor went on to say, we would be wasting our love on her. "Why not adopt another child in Katie's place," she suggested. One who could return our love.

I hugged my child all the way home. I worried that she had "sensed" the abrasive consultation. I worried about my husband's reactions and those of our older daughter. I could feel a ghastly hollow detachment and isolation envelope me from head to toe and side to side, but not before we stubbornly and from the gut answered that ugly challenge with a loud and firm "No!" as we arrived in our driveway.

There was no early intervention as we know it today. I think that family caregivers do what comes instinctively in that situation. But the added knowledge of various therapies and techniques are crucial because it can possibly save a marriage from divorce or desertion or noninteraction. Or it can give parents courage to hang on, not to institutionalize, and something constructive to do with their hands and minds.

A parent of an involved child becomes afraid of the unknown; isolated with his or her own strange emotions. I remember asking my mother which I should tell people that Kate had; cerebral palsy or mental retardation I knew absolutely nothing about either. If we had had a local organization and a national organization like The Association for Persons with Severe Handicaps (TASH),* at that time, our family life and Kate's education would have been much more directed during those crucial first learning years.

Parents, today, still must deal with medical staff and other providers who are clearly uncomfortable with their roles. This is due in large part to the scarcity of enlightened educational programs in medical schools and universities.

I have spoken to students in a public health course who primarily were concerned with how much parents should be told. "Everything," I replied. I must emphasize that by everything I mean that new parents should be given information on all medical options, all educational options, all appropriate methods and therapies, all developmental stages, and the potential impact on siblings -- all right in that birthing room.

I like to tell the true story of a magnificent friend of mine who is a highly qualified professor of special education of the severely handicapped. She flew to Florida recently when she learned of the birth of a baby with severe multiple handicaps to her friends. She lent immediate support, facts and hopes to those new parents before they went home with their baby. They knew what to expect and when, who could be coming into their home to work with that baby and why.

---

* The Association for Persons with Severe Handicaps (TASH),
7010 Roosevelt Way, N.E., Seattle, WA 98115; (206) 523-8446

I still wonder (guilt) what happened during my pregnancy that caused our much wanted child to be born with handicaps. No doctor has an answer. (As the March of Dimes TV ad says: Parents of handicapped children aren't evil nor do they deliberately have babies with handicaps.) When we learned in August, 1983, (Kate was 14) that she had also been deaf since birth, all my old fears and questions resurfaced. Did I do something wrong Maybe my ancestors are to blame. Maybe my husband's. All of these are natural reactions. My point is that relevant information from the very beginning is the key. It is the cement that can glue a family together in horrendously stressful times, not to mention Faith and Hope.

Implications for Families Providing Habilitative Care

Today when a family is presented with the knowledge of any disability, all sorts of supporting arms should be available to swoop around the family, arms from physicians, social service agencies, religious institutions and the local communities alike. These attitudes should promote confidence, hope and a "we'll learn to live constructively together" attitude. This must happen in those first hours, days, months and years. Service providers (e.g., case managers, parent trainers) must be trained to provide expert consultation and quality care for that child and its family, which will be in a state of shock and then confusion, perhaps for several years.

Services That Families Require

Kate needs partial assistance and partial independence in every phase of her daily life --dressing, toilet schedule, washing, eating, leisure activities, positioning, stairs, and nonverbal communications (She does not need assistance to either give or receive love!). This takes careful planning on the part of her caregivers. It requires physical stamina, knowledge, creativity, dedication, determination, and the ability to drum up a positive outlook each and every day. It requires, for me, one activity each day which I can anticipate. This will focus my mind on getting through the repetitive drudgery of many everyday tasks. Every family with a member with a handicap has extraordinary daily tasks to perform.

Medical and Special Equipment needs are repetitive and usually lifelong. Appointments. Records. Medical insurance. Forms. Travel. Reports. Parents are asked time and time again to provide the same repetitive information. This is time consuming and can be a cause for stress. Medical costs are unbelievable. A scoliosis brace is $900.00. An auditory trainer is $700.00. A hearing aid is $400.00. Only recently did we learn about P.I.C. (Prolonged Illness Coverage) under Blue Cross and Blue Shield. But one doctor said he would not recommend a larger brace because of the cost and the short period of time it would be needed. But he did admit that Kate had almost outgrown the brace! Most health policies do not include dentistry, which is vitally important to a person experiencing handicaps. In Massachusetts, one can receive dental services at state institutions for free. But our children can and should go to a dentist in their community, like their siblings and parents! Ramps at home are expensive to build but are so necessary. Vans with lifts. Special chairs. Fancy catalogues with fancy prices that institutions can afford but which families cannot.

The same problem occurs with sitters. It is vital that caregivers have time for themselves. Go out in the evening. Go on vacation with and without family. The problem is fitting in to the mold of a sitter -- her hours, her constraints, her transportation. Sometimes I feel as though I am being freed to leave the home only on the sitter's terms: her free time and her rate.

Respite Care is a term I dislike. In many states it is hard to get. It is bureaucratic. It is unreliable. It is insufficient. It is not immediate. When I feel exhausted, I must know that I can anticipate relief tomorrow at 10 A.M. That very knowledge is, in itself, one of the controls I have learned to use constructively. I do not plan my frantic moments. Currently, in my state, the Department of Social Services may authorize ten days of Respite for each six month period. Parents may choose to use half days (five hours or less) or a combination of full and half days. A "full" day is ten hours only. At my house, a full day is 24 hours!

Our primary preference is to find someone, living in our community, who could simply become a welcomed member of our family when here. If I can find a person who has been exposed in a personal way to handicaps so much the better. I prefer a person who will continue my routine. I do not require fancy training. I think I can provide that myself. Fancy training can create preconceived misconceptions about a child's abilities and how s/he should be treated. Often those preconceived notions do not fit, but are difficult to correct.

I do require an individual, male or female, who will talk with Kate, as a sibling might, constantly commenting on the happenings of the moment. This, I have discovered, is hard for some people to do. Maybe it reflects their own insecurities. I need someone who will help Kate to fill her day with quality activities even if Kate can only partially participate in those activities. Let's say that another way: if Kate can push the grocery cart and can behave appropriately in the grocery store, then grocery shopping is on her list of "let's do." That list might contain trips to the library, the zoo, the mall, the post office, the movies, the playground, and so forth. All one needs for these activities is common sense. Through prior experience, the knowledge of Kate's capabilities and preferences and the knowledge of one's self supports confidence and love of one's fellow man. Period.

If Kate's brace needs changing, I'd prefer to teach that. I'd prefer to teach my sitter the techniques we are using to encourage self-feeding. I have a faith that families can give a sitter that certain kind of positive attitude which is the motivational springboard for our children. I have learned about braces and feeding from professionals, and now I can share it with other community members.

Parents are always being challenged to make Home Adaptations. When Kate was using a fourwheeled walker, we paid a carpenter to install shingle slats on either side of all thresholds to enable its wheels to cross over, thus promoting independence. I fashioned a guardrail across the top of the stairs.

Our yard helper, a local college student, made some wooden book rests, a swing frame, and a prone board and balance board to the Physical Therapist's specifications.

A carpenter installed parallel bars and a cheap mirror under a window so that Kate could perform her physical therapy exercises of sit-to-kneel and pull-to-stand where she was most motivated -at a window. The carpenter made an angled footrest to the kitchen chair for better positioning and adjustments.

Our bathroom has grab bars installed around the tub. I found them in a catalog which now will not accept individual orders -only institutional ones.

We have made numerous adaptations to several bicycles along the way -training wheels, welded handlebars, banana seats, velcroed foot straps.

When we buy a new car, the seat's accessibility is a major factor. Those needing vans and lifts endure tremendous expense. And what about resaleability.

I am not knowledgeable about Medications because Kate does not need them. I wonder how families who do purchase many medicines pay for them. I do know they are increasingly expensive.

My husband has put together, with the guidance of a professional, several electronic Leisure and Educational Activities for Kate. For instance, consider a Kodak Ectagraphic Slide Projector with synchronized tape cassettes. It has an on/off switch operated by Kate and a push panel wired to the projector's screen that enables her to change the slides by pressing the panel. The slides are pictures we have taken of family occasions and pages of favorite books. Our voice on the tape reads the text. Both projector and tape are fixed to a timer so that Kate must press the panel to activate the slide and hear the next part of the story.

He has also organized a tape recorder with a timer and a color organ (Radio Shack) so that when Kate presses the on/off switch a cassette tells the story of Louisa May Alcott's Little Women. For instance, colors are flashed to vocalizations for as long as the timer is set. Both slide projector and tape recorder are precursors to work with computers in the competitive marketplace in Kate's home town!

We got our "Handicapped Person" license plates mainly to enable us to park near the medical facilities we frequent. This is a great help physically for everyone, especially after a long drive and before beginning the return trip. I hasten to add that on pleasure jaunts we park in regular slots. Walking is part of Kate's physical therapy.

I am sure that a majority of parents are not knowledgeable about how to activate a good Financial Plan and Will for their children's futures. It is hard enough to think about your own will. Trying to anticipate what the situation will be when you die so that plans function smoothly for your child is an extremely stressful worry to most of us. The terminology, laws and concepts are difficult for us. We postpone. There are workshops; some literature is available. So are hefty lawyers' fees. Each state in the country is different. We worry!

Large families tend to depend on one member to be the primary caregiver of the future. This is often not an appropriate responsibility. It must be voluntary. But the issues must be addressed by all involved.

Some parents want to know if Medicaid can be utilized for Respite Care. One 17 year old boy who is hearing impaired, nonverbal and aggressive needs a male helper with him at home. Local agencies will no longer provide the service. His parents are being urged to institutionalize him. Any human with a hearing impairment is under great stress constantly. We need to find support and comfort for this youth and his frantic parents in his own home environment. How can we help?

In many states, like Massachusetts, Home and Health Services are being utilized more and more by parents who cannot find regular sitters and whose health insurance plans or Medicaid will cover the extremely high cost. But these services can be expensive (e.g., $80 a day). The Home Health Aides are medically trained, and serve a real need. But the cost is outrageous and not all families need the medical input.

When my widowed mother became ill, sold her house and was hospitalized, I would have liked very much to have her stay with us during her recuperation and subsequent housing decision. Her interactions with Kate and us would have been very valued. But my prior experience locating sitters for Kate scared me. And I was uncertain about the close quarters, nurses aides she would require, and my questionable ability to calmly juggle husband and child, mother and constant outsiders in our house. I should have taken the chance. But I did not know of a definite safety valve I could turn for me. I would like to see changes in the current support system which would help others instinctively struggling to hold families together.

Family Well Being

Some families disintegrate but many solidify when they learn they have a disabled member amongst them. Much depends on communication, that old buggaboo and hangup. Egos have become damaged. Guilt and anger and confusion are pervasive. Parents must communicate with themselves and other siblings. If that is difficult, the strongest must reach out to a trusted friend, counselor or another parent or a religious leader. Sometimes another family member can be helpful. By talking, the stress and uncertainty, which, if left unchecked, could lead to an out-of-home placement, are brought under control, and recovery to some degree of normalacy can begin.

Most people in society's mainstream have yet to understand the joys and potential that handicapped individuals can bring to a family unit. To unearth these hidden benefits is very rewarding. They occur usually when you least expect them, so a day-by-day philosophy is natural.

Marital relations reflect the stresses and joys of the family situation. If one has come to the marriage ill-equipped to handle any major adversity, life will be stormy. If both partners can hang in there long enough to recognize what can be changed, then the relationship becomes one of constructive advocacy.

It is safe to comment that more couples today are discussing the "what ifs" of producing a child with handicaps, before marriage. Modern medicine is more knowledgeable.

Inspiring new friends will be made. Some old ones will drop by the wayside, unable to understand your new priorities and time restraints. I recall a small dinner party when our friends who opposed a group home on their street moved to the other side of the living room for the rest of the evening when they learned we were proponents. It is difficult.

Researchers are just beginning to delve into the world of siblings and their role. There will be resentments and hardships. Sharing the load in a positive fashion is constructive and one of the elements of family life. The potential for sibling growth through sharing is there. I like to envision each sibling leaving the nest as an ambassador to the world outside. I am happy to report that Kate's older sister, who is 28 and a reporter for United Press International in New York City, is not only an ambassador but a great support to Katie, who blossoms when she comes home, and to my husband and me.

Siblings may benefit from genetic counseling. Siblings need time of their own. They need to be recognized for their own achievements. There is a trend to feature "Sibling Panels" at conferences today. We have much to learn about their joys, fears and frustrations. Siblings may often be found in professions related to the special needs field.

The extended family should also be considered. Aunts and uncles, grandparents, in-laws, a particular neighbor, a peer buddy from the community, a peer tutor are all the kinds of arrangements which are homespun and community-based. TV ads proclaim Adopt-a-Grandparent, and Big Brother/Big Sister programs. A good example is a television show hosted by Jack Williams on Boston's TV Channel 4. This program, called "Wednesday's Child," promotes the adoption of children with a wide range of handicaps in Massachusetts who need a family to live with. He received a Media Award from T.A.S.H. at its 11th Annual Conference in Chicago, November, 1984.

Recommendations for Improving Support Services

The support services available in many states are a great help to families. They can, however, be improved. Please consider the following recommendations:

Information and Training

1. Medical and educational personnel and citizens of the community could benefit from increased Training and Exposure to Persons with Disabilities with an emphasis on understanding families and their needs. This includes doctors, nurses, case managers, parent trainers, and to a greater involvement community citizens.

2. Parents continue to need Information and Training, not to be parents, but to learn how to gain access to the confusing systems which surround them, and the latest techniques for improving their child's overall functioning.

Adapting the Environment and Special Equipment

3. Adaptive Equipment Exchange and Rental Groups are a vital service expansion. Some are scattered across the country. One is barely operating in my area but not for renting equipment, only for borrowing. I suggest that sensitive items, such as auditory trainers, computers, Braille typewriters should be included. Because they will need special servicing and maintenance, they could be donated to and rented from a larger pool. Presently, one borrows a limited supply from one's school system, but there are no backup machines available and valuable time is lost to that student. The public is totally unaware of the problem.

   In our situation, Kate is lent an auditory trainer by our school system. At year's end, that equipment goes back to the manufacturer for servicing. Kate's "Phonic Ear" package was lost in the mail for a month, and there is no substitute equipment! Her summer educational program, so long fought for through the appeal system, suffered.

4. In this connection, the Media should be utilized (electronic and print)to bring the equipment needs of our population to the attention of prime manufacturers, foundations, church groups, and so forth. T.A.S.H., for instance, has a National Media Watch which is set up through its chapters to respond to any type of media, anywhere, good and bad, with speed and accuracy concerning any persons with severe and profound handicaps.

5. Housing Adaptations should receive greater attention. After all, the entire family functions in an environment called "home." Home should be a place that is structured to foster independence in the disabled child and to ease physical demands placed on caretakers. Ramps, grab bars, and other adaptations should be made available to families.

Direct Services

6. Skills Instructors are needed who come into your home on a regular basis to work on skills important to the child in that environment (eating skills, and other daily living skills). School personnel must coordinate their activities with any such instruction that occurs in the home to promote skill generalization.

7. High School Peer Tutors are noted by name in town newspaper columns. Perhaps, more of them could be enlisted to act as skill instructors, care attendants or just plain friends
8. Responsive and sufficient Respite Care is virtually nonexistent. I am aware of two current projects to document the situation. Standards vary greatly. Rates are subminimal. The need is acute. Parent cooperative arrangements are one answer.
9. Families need Financial Reimbursement for educational litigation. Poor and minority families are unable to upgrade an educational placement. Advocates are scarce. Lawyers are expensive. Parents are not reimbursed for their efforts, school systems are.
10. Early Intervention must be maintained and creatively expanded.
11. Integrated Recreational Programs that are run by local townships are needed by persons with severe handicaps.
12. Expanded involvement of Churches and Community Organizations in the lives of persons with disabilities would be welcomed.
13. There is a need for development of Accredited Summer Camps appropriate for all handicaps. Camperships. Both are in minimal supply. Both are so important in social development.

Support Networks

14. I believe that parents need outlets to tell and write their stories in order to communicate their experiences to other parents and to spur changes in the system.
15. Parent Advisory Committees (PAC) in school systems are mandated but not enforced. These committees should be strengthened to reduce the costs of appeals and out-of-school placements prompted by inadequate local services.

In conclusion, professionals, bureaucrats and others committed to helping families should be reminded that parents really do want to treat their child with disabilities like their other children. That is, they seek to be primarily in charge of shaping the course of their children's early life; that is their parental responsibility. Moreover, those wishing to support family efforts must realize that no two families are alike. Each responds to the advent of disability differently, and requires different types and amounts of services.

Given these considerations, services should be designed around two fundamental principles. First, a comprehensive and flexible service menu must be available so that service plans can be individualized. Second, families must be empowered and encouraged to embrace a primary planning role so that they can direct the course of services and escape continued dependence on bureaucratic systems. In essence, family support systems must be maximally responsive to the needs of families; they must be family driven.

THE PERSPECTIVE OF A PERSON WITH DISABILITIES

by

Susan F. Lamb

Call me Susan. Call me Matthew. Call me your daughter or son. Call me pupil or client. Call me cripple or dummy. Call me developmentally disabled. Whatever your label, I am, I live. And your attitudes about my limitations and future determine the fullness or paucity of this life I have been given. I was not born with an awareness of the meaning of "severely disabled." I didn't understand why the dreams my parents had for me had been shattered. I had not been excluded yet from schools, libraries, museums, parks or a place in society. When I was small, nestled in the soft padding of my special stroller and a child shrilled as he passed: "Why is she bent that way?," "look she's got no legs;" or "Mommy I don't like ugly people like her." I couldn't understand why the "Sh-h-h-h" of the child's mother sounded so angry at me. I had been introduced into the harsh reality of attitudinal and architectural barriers. For a person who is moderately or severely disabled, these barriers create the loneliness and isolation that is ever present in our lives.

Whatever the disability, race, sex, religion, nationality or income group attitudinal and architectural barriers frustrate the life of the individual and his/her family. Consequently, the purpose of this paper is to personalize the consequences of these barriers on the life of the individual with the disabling condition and his/her family. It is divided into three parts:

1) Self awareness, integrity and disability; 2) The ultimate objective: Independence; and 3) Some crucial concerns.

Self-Awareness, Integrity and Disability

Like all children, I remember scrutinizing my body with the sharp eyes of childhood. Because the other children would tease me, I remember my only playmates were my brothers and sisters. I remember when no one except my Mom would take the time to understand my speech or to explain that the family could not go to the movies, parks or zoos because there were no ramps. Gradually, you begin to absorb the message: "YOU ARE NOT OK."

> *People stare at you if you're different. They can make you feel like a Martian. I have never wanted to go out because I was so self conscious. My family would say "You have to go out, we'll take you to the beach." I wouldn't. So my father would get off work at night and we'd go to the movies. The only show I'd go to was the late show. . . My father would wheel me out as soon as the lights came up. -- Terry, post polio*

The prevailing thought in the rehabilitation and medical community seems to associate disability with disease. ARE YOU SICK? Parents attack your body, twisting it, bending it. Doctors stick it, poke it, cut it. The goal: GET WELL. Make the most of what is there. Try harder. Never give up. One more surgery, a different doctor, a change in diet, perhaps that will help. By the time you are six, you know some great tragedy has befallen you and your family. The stress is immense during your rehabilitation period. You must try to look more normal. You must not cry or complain too much. Often during this period in a disabled child's life, he or she is discouraged from asking about the nature of the disability or what the future might mean. What is often overlooked by parents and medical personnel is communicating with the child, what IS happening or what MIGHT happen. To not inform a child of what is happening makes the child vulnerable to unneccessary fears.

> *I don't like being alone because it gives me a feeling of loss. I think it all started when I went to the hospital and was separated from my family. There was almost no communication. I think I have been alone for so long and for so many years that I hate the idea. -- Lois, deafness*

Many disabled persons believe that only their families care enough to help them or are interested in them. Inactivity of the body and passivity of mind during a young child's early years will atrophy the spirit as well as the body. Even a young child needs to understand and be encouraged to assert him/her-self, to ask questions or to seek help from those outside the family. Because, for so many professionals you are just another case and you are assumed to have no need for privacy nor a sense of modesty, a child needs to know the answer to "Why?" and "What for?" and "What is it?"

> *We had monthly visits by an orthopedist, who would come like a circuit judge to the school. . .I would have to get out there in my underwear in front of the doctor, the physical therapist, a couple of teachers, maybe the principal, other kids and parents. I'd be paraded around and had to listen to my case being discussed. -- Vickie, cerebral palsy*

Disabled persons must also cope with stress stemming from a recognition of the inordinate demands made upon parents and siblings for their time, their patience and their physical endurance. If left unchecked, this condition can frustrate a disabled child and promote guilt. Likewise, the family may resent the extraordinary caretaking responsibilities. It takes time to realize that alternate care arrangements can help.

Unpaid assistants (family members) provide care for disabled persons out of love and a sense of responsibility. That is what is expected from family members and it works just fine until one person does all the receiving. Without recognition of the needs of the person doing the giving, burn out occurs on both sides. A general erosion of the spirit occurs. For those of us receiving the care, we often feel guilty when we sense our parents have sacrificed themselves for us and are quick to point out that fact. Martyred parents are seldom appreciated. Burn out in most cases is the major cause of deterioration within the family.

Brothers and sisters, just like parents should not be expected to devote their lives to the heroic cause. Siblings adopt the attitudes of their parents. Responsibilities are so enormous when caring for a severely disabled child, brothers and sisters often become surrogate parents. Brothers and sisters are expected and needed to help, to give up play time, to take their disabled sibling with them when they go out, to baby sit, to feed, to bathe, to lift things. It is natural for them to have feelings of both love and jealousy. It is most difficult to answer questions from playmates such as: How does your sister go to the bathroom? Where does she sleep at night?, Why does your brother's face look squished.

Believe me, it is not any easier being the disabled child. When you feel clumsy, worthless, unattractive and are subject to constant supervision by your family, it is very hard to not become sullen, demanding, jealous and manipulative -- in short, a tyrant.

WHY DON'T FAMILIES RECEIVE SOME HELP FROM THEIR COMMUNITY OR THEIR GOVERNMENT? Why isn't there a uniformity in the scope of community based services programs from state to state? Why does a family often have to reach poverty level before they can qualify for medical care or other services like homemaker assistance, respite care, personal care, medical equipment, physical or occupational therapy or adult day care? It has been shown time after time that when home health aides and services are available to families caring for a disabled member, the savings to the taxpayers and to the fiber of the family is staggering. Families need these support services in order to maintain their self sufficiency -- both economically and emotionally.

Having a disability is only a part of a disabled person's life. To the individual and those who care and love for him/her there are other sides to that person. It's the life of the disabled person that matters. How to preserve, respect and enhance that life is the ultimate goal of both the parents and that individual with the less than perfect body or mind. Nondisabled and disabled family members need to interact with their environment. They must be able to explore, manipulate and enjoy their world together. Architectural and attitudinal barriers must be eliminated within communities. Within our nation's special-needs families, the integrity of these families and the self respect of EACH member of the family depend upon the elimination of those barriers.

The Ultimate Objective: Independence

Besides being Mom and Dad, parents are our physical, speech and occupational therapists. Each improvement in our bodies is heralded as "progress." With each success (head being held up, feeding yourself) we are being encouraged to believe we can do more.

> *The other day I was on the bus with a cerebral palsy girl who usually left her mouth slightly open. Was I ever glad that my mother said "F-f-f-f-t-t-t" (short for flytrap) to me whenever she saw my mouth open. . . She could have yelled "Shut your mouth" which I would have resented. -- person with disabilities*

It is very difficult for us to face such fateful questions as: Who will feed me? Dress me? Talk to me? What will happen to me when Mom and Dad are gone? The rite of passage for most severely disabled adolescents is the terrorizing awareness that if you should prove incapable of leading an independent life (and you are told this by society in so many ways), your future might be institutionalization. Having the self-confidence to acknowledge there might come a day without your parents to protect and care for you comes only with acquisition of daily living skills.

The struggle to define independence is entwined with the attitudes you have about yourself and those attidudes others have about you. Far too many disabled young adults learn to subordinate their own interests and dislikes. For a disabled person, maturity often means learning to accept the roles and expectations that have been prescribed for your particular disability group.

> *The sight of someone who is physically twisted, in a wheelchair or who has the gait of a drunk exhibiting contortions and poor balance might elicit in you fears,*

> *feelings of inadequacy. It might bring out your protective father or mother instinct. It is sometimes hard to conceive that someone who is really screwed up physically with the speech of a drunk or no speech at all has the same needs as you and perhaps in some cases a higher intelligence than yourself. --- Elizabeth, cerebral palsy*

I can assure you that people are looking at Elizabeth wondering what will become of her or rejoicing that God didn't zap them. She is wondering: Am I somebody? Do I look that grotesque? Will anyone marry me? Will I ever work? These are all questions asked by anyone who searches for meaning to their life.

Where do you build the self-confidence to know what you are capable of doing? Within the home is where it begins.

> *Because of my physical condition, I was given limits by people. They assumed that they knew all about me because they read about cerebral palsy in their college textbook. -- Lauren, cerebral palsy*

Family schedules are hectic. A disabled young person wants to do his or her part to help out. However, everyone, including parents, is preoccupied with how long it takes to accomplish a task or the awkwardness demonstrated to carry out the task. Attempts to assert ourselves are too often dismissed with "You'll tire yourself, let me do it." This is a mistake. The emphasis should be on self sufficiency whether the child is disabled or nondisabled. The more dependent you are on your parents -- when you believe you can do something for yourself -- the more surly you become. Your family become servants.

A recent example of this concerned a young man I know. He was ashamed that his mother still helped him bathe. He didn't need help but was afraid he would break the glass shampoo bottle. Finally he told his mom. She substituted a plastic bottle and this young man took charge of his personal hygiene. A false dependency is most damaging to your self-identity and relationships with others. Parents should encourage attempts to help with daily activities. Agreed, it takes twice as long to make the bed. Agreed, it is easier to let someone else dress you. Agreed, a sister doesn't object to getting the glass of water. However, if persons with special requirements believe they can make their bed or dress themselves or get their own drink of water, it becomes demoralizing to have their competence challenged. Even if only a part of a daily living skill, such as cooking, dressing, bathing, cleaning, managing and budgeting money or locating community resources is feasible, that skill should be used. This knowledge ultimately will better prepare them to live a life outside their family.

As important as it is to know how to carry out a task, it is equally important to understand how to direct someone on the best way to assist you. Thoughtful management of those extensions to our bodies require that the person being assisted be taught how to give directions, interact with another person and exercise patience. Preparing the disabled person for a life without his/her parents or accustomed caretaker means the disabled person must learn to exercise responsibility in order to build independence. Independence is an attitude. It is not necessarily doing for yourself, but understanding how to choose and control the options at hand. Working, despite leg braces, fused limbs, spasms or restricted hearing, creates an assertiveness which reflects a positive affirmation of one's best interest.

This assertiveness is revealed by statements such as: "Thank you, I can tie my shoes." "I can push my chair." "I can pick up the book." "Thank you, I can make my own decisions."

One of the earliest ways a young disabled person learns how to be assertive and to practice cooperation is in school. About ten years ago, handicapped children were routinely excluded from school or placed in inappropriate classes. With the enactment in 1975 and enforcement of the Education for All Handicapped Children Act (P.L. 94-142), handicapped children now have access to a vast array of educational services. With P.L. 94-142 each child has his her individual needs met in the least restrictive environment. Issues relevant to placing moderately or severely handicapped children in special or mainstreamed classes are vigorously debated by educators and parents. Whether the child is in a segragated classroom or taking his or her chances with nondisabled children in integrated settings, the school experience is deeply felt.

> *When people ask me if I'm in special ed, I get embarrassed. I'm afraid they're going to make fun of me or laugh. Sometimes I just say "Yeah." They ask why and I say because I'm slow. I used to get laughed at. -- Cheri, learning disabled*
>
> *I don't like it in this school. I would prefer to be with deaf people. I don't try out for sports and I would in a deaf school. -- Becky, deaf*
>
> *I remember interacting in school with other kids who were disabled kids. . . We were all the butt of everyone's ridicule and exclusion. There was a camaraderie among us because we were mutually hurt... That's had an influence on my life. -- Ann, blind*
>
> *Our little girl is 2½ years old. Thanks to infant stimulation, she is going far beyond the doctor's*

> *expectations. We believe infant stimulation and early intervention are the key to helping developmentally disabled people to a more productive life. We believe every parent and child should be given this opportunity however it is NO LONGER AVAILABLE in our area. -- Letter from a parent*

The problem with education does not lie in a lack of funding for programs but in the attitudes of program officials. Many of these people view education, especially higher education, as an enrichment experience not job preparedness. Such an enrichment experience will enable the child/adult to pursue intellectual activities during the anticipated prolonged periods of isolation. In other words, nobody expects you to work, to feed yourself, clothe yourself or support yourself. It is very hard to develop mature and responsible habits when nothing is expected from you. Everything you do is "wonderful...considering." Educators must stop promoting restrictive curricula for disabled students. This is particularly evident in the math and science areas.

Another practice that discriminates against our attempts to educate ourselves involves use of various competency exams. Many of these exams test for middle-class children's everyday knowledge. When I was in the eighth grade, I took the achievement test given to all the students. I scored high in verbal and math ability. However, I was at the level of a three year old for spatial relations. In other words, I couldn't put the square in the circle. Small wonder, when I had minimal use of my hands and no use of my legs. Before administering these exams, educators should probe the student's problem solving abilities and street wisdom. Ask any parent, they will tell you how resourceful their disabled child is. Educators should be aware of which tests are best suited for which students.

Lastly, there is a great gap in educational opportunities for autistic children. For preschoolers, programs are few and far between. Occasionally, these children are served in community preschool programs sponsored by associations for retarded citizens or Head Start. They are, almost always, placed inappropriately. They never receive the year round services they need. Twenty-four hour, year long educational and treatment programs are scarce. Those programs that do exist are expensive and most families lack the resources. The bottom line is that it is the rare autistic child who receives appropriate services. Consequently, a great many adults with autism become institutionalized for life. Why can't these children receive what they need to stay with their families?

Section 504 of the Rehabilitation Act of 1973 (PL 93-112) is considered by many of us, who have struggled all our lives to be first class citizens, to be our civil rights act. The basic goals of this legislation and other recent legislative initiatives [e.g., 1978 Amendments to the Rehabilitation Act of 1973 (PL 95-602); Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103); Developmental Disabilities Amendments (PL 98-527)] grows out of such principles such as self help, self direction, deinstitutionalization and a rejection of the medical environment. Self help groups and federally funded Protection and Advocacy projects have become the catalyst for these goals.

> *All the time I was growing up and afterward there were a lot of buildings I could not get into or had to have people with me carry me into them. I really feel, particularly in public buildings, that we have the right to go into any room we want. When I know I can't go to the bathroom, I get pretty nervous. -- Terry, post polio*

With the passage of these laws for the first time people with disabilities can assert themselves as first class citizens. You have rights to education, to go into polling places, to control the treatment of your body, to work for a living -- YOU CAN HAVE A FUTURE is the message to those with disabilities.

> *Disabled children have to believe as much as any children in the world that they can continue to live and be happy and functional...that there is a future for them. -- Linda, post polio*

The independent living movement serves as an important model of self help and outreach embodied in the disability rights legislation. Three basic principles govern the independent living movement: 1) Disabled persons design and run their own programs; 2) they are community based; and 3) they provide services and advocacy. Title VII of the Rehabilitation Act Amendments of 1978 (PL 95-602) provides over 80% federal funding to Independent Living Centers. The financial dependence of centers on such funding is beginning to cause serious concerns for the future. Competition is keen, and existing centers are pitted against newly created centers. Independent living centers are too valuable a community asset to be allowed to be strangled for a lack of funds. Parents and advocates must work to save them.

Protection and Advocacy Programs (P & A's) are a second indispensable source for ensuring that the family and the developmentally disabled person receive all the rights and services to which they are entitled. Protection and Advocacy programs, as established in PL 95-602, are required in all states. P and A's can provide supportive, investigative and legal assistance to enhance the welfare of developmentally disabled children and adults.

> *When she moved into this neighborhood, I was the only one trying to help her... And her parents are not trying to keep her in proper care. They take all her money and spend and drink it up in liquor and beer... They are the ones trying to mess up her life by trying to put her in a home that she really doesn't need to be in. All she wants is to have a free life... She knows how to dress herself, and cook, and wash but when it comes to business things she comes to me for help -- a neighbor.*

This is part of a letter received by the Alabama Developmental Disabilities Advocacy Program. Hundreds of similar letters are received each year.

Helping developmentally disabled people to accomplish their ultimate objective, independence, requires effort on the part of the disabled individual, their parents and the community. The individual must put effort into becoming self-motivated. The parents must teach their disabled child daily living skills to foster the self-confidence needed for independence. And the community must support these efforts through integration of the disabled into the community.

Some Crucial Concerns

After reviewing the relevant literature and speaking to a number of persons with disabilities, it is clear that a variety of service needs exist. My purpose here is not to elaborate on each service, rather, I want to highlight five service needs of extraordinary concern: home safety and housing adaptations, day care, transportation and architectural barriers, body image and sexuality, and the future away from one's parents.

Home Safety and Housing Adaptations

In my family and most families where one or more members are physically disabled, home safety is an especially poignant concern. Enlisting the aid of neighbors, role-playing emergency situations with family members, having every family member pledge never to leave the disabled member alone, does not guarantee that we will not find us left by ourselves. Day after day across the country, emergency situations occur: fire, personal assault, or accidents. When emergency aid is needed, it is often extremely difficult for us to summon help. Why? Two reasons. First, though police, fire stations and hospitals, to name a few, are supposed to have communication devices that accommodate those of us with severe physical or speech or speech and hearing limitations (in accordance with Section 504 Rehabilitation Act of 1973) few have such devices. Cost is not the reason why few communication devices are found within the community service departments since they are relatively inexpensive. Current policies are based on inaccurate assumptions about the lifestlyle of a person with a severe physical limitations. Such assumptions include: 1) I will always have someone with me if an emergency should arise; 2) I will never have an emergency; or 3) I will never need to seek aid for another person in crisis. Another reason help is difficult for us to summon, is the lack of familiarity among most emergency personnel (i.e., operators, ambulance attendants, police, etc), with disabled people and their needs. People who have responsibility for assisting others need to know about different disabilities.

Day Care

Day care and home safety go hand in hand. In many states school services are designed to serve disabled children younger than five. In addition, Head Start serves some children in some areas. But from state to state the quality of existing services varies and they are not uniformly available. Severely retarded children/adults may be forced to wait three to four years for limited space in adult activity programs. Summer programs for severely disabled children are virtually non-existent except at parental expense. If the majority of households with children are headed by women, and society says it's better to work than be on "AFDC," and a good percentage of those women headed households that have one of those 2,000,000 chronic physically or mentally disabled children, where is that mother supposed to put her child when she goes to work?

> *Sue, my daughter, age 6, goes to East Elementary School Special Education Class. Before she was six, she went to the Cerebral Palsy School here all year long. I checked about her going there when school is out for the summer and the CP school said if they didn't get funded for extra children they would not be able to take her. Sue needs to continue her speech and physical therapy all the time, three months is too long to be without help. Day care does not take handicapped kids, so if I can't put her in the CP center this summer, I really don't know what I can do. I work and I need to have her taken care of just for the summer.*

Transportation and Architectural Barriers

If you use a wheelchair, crutches or have sensory limitations, transportation and architectural barriers are giant problems to overcome. From middle childhood on, especially during adolescence, friendships and activities are nourished after school. Mobility is paramount to recreation and socializing. You can't go anywhere, do anything, meet a friend unless your parents take you. The hurt feelings and rejection that come from being dependent on only your family to take you places boils down to: "You do not have a private life." The more severe your limitations and the older, consequently heavier and larger you are, the physically more difficult it becomes to take you places. Every outing has to be carefully evaluated and planned. Spontaneity is replaced with assessment of the effort involved. The harsh fact is that the solution to this problem is costly. In some communities, services such as Dial-A-Ride, exist and, in rare cases, some accessible public transit is available. However, in most cities the programs are grossly inadequate to meet the demand for services by disabled children and adults. Transportation may be costly but the cost must be balanced against the isolation and despair for countless disabled persons.

Body Image and Sexuality

Why should spasms, wheelchairs, mental acuity or sensory awareness change a person's right to express sexuality or experience intimacy? Intimacy is not exclusively the special closeness defined by physical proximity or agility. Rather, for most people it is the sense of comfort, acceptance and trust shared with another human being. Yet, many people would be surprised and slightly uncomfortable with Sara's desire for and expectation of fulfillment. Many people, parents, teachers, counselors and medical personnel included, ignore the sexuality of the disabled adolescent and adult. We are assumed to be either asexual or impotent. This denial of sexuality is the cruelest attitudinal barrier faced by someone with severe disabilities.

> *I was born without legs and with a right arm that ends where most people have an elbow. It's an unusual body but it is a body. It houses a living person and lets me do many of the things I want to do to fullfill my life.*
> *-- Sara, amputee*

What you see in your mirror affects the decisions you make regarding: How to take care of yourself; what you think you can do, can't do, won't do, want to do; and what kinds of relationships you choose to have. The reflection you see tells you how to look to those who love you, the way you need to look, the way you look to strangers. The scars, the curvatures, the spasms, the slowness makes you appear physically different from those images on TV or people around you. From these sources it appears that loving depends on body fitness. The implicit message is that it is unnatural or pathetically unrealistic to expect to experience various relationships with other disabled persons, or even more maladjusted, a nondisabled individual. It is hammered into your head by parents, rehabilitation and medical personnel, as well as architectural and attitudinal barriers found in communites, that you are incapable of having a deep relationship with anyone other than your parents. After all, who else but your parents might love someone so different and dependent.

Tragically far too many young disabled people conclude they will never have a chance for a normal relationship. The comfort, acceptance and tenderness found in a relationship is assumed to be forever denied them. Why? Because of mental retardation, epilepsy or autism. No! The reason is those who see our unusual bodies assume the basic human needs and desires to love and be loved have been subjugated to the physical, emotional or mental difficulties that must be overcome. They are mistaken.

But how does a parent and/or those who care encourage a 15 year old, who uses a wheelchair and whose body is very malformed, to smile at the image in the mirror? They might: 1) acknowledge and affirm the young person's sexuality; 2) encourage social situations; 3) push for clearly understandable sex education materials in schools or have them available at home; 4) keep pictures of the persons with the disability around the house; 5) teach as much self care as possible; and 6) discuss financial and physical arrangements which must be made if two severely disabled and unemployed persons should desire to marry. The point to remember is that the disabled person's body contains the gift of sexuality just as the nondisabled person's body does. Whether that gift is rejected or accepted is determined by the attitudes of those around us.

A Future Away From Parents

It can be said of many parents of a disabled child that they have been endowed with the courage and inventiveness to cope with the situation. Perhaps it is true that God sends "special" children only to "special" parents who have the ability to adjust. However, there is one inevitable situation few parents actually plan for: What will happen if I can no longer take care of Mary, Jimmy, Sally? Or worse, when I die, where will they go? How will they manage?

Coping with aging can precipitate changes and stress within the family of a developmentally disabled person. Growing older is difficult for all of us. We are reminded with the weakening of our body and senses that in American society the aging process represents a change in status from being a responsible adult to becoming a dependent adult.

For the parent who has the responsibility of caring for a developmentally disabled adult, aging has frightening implications for their lives. Having once accepted the obligation of parenthood for a moderately or severely disabled child (i.e., the physical and emotional care giving and financial support), surrendering those obligations to another is out of the question. It is terrifying for most aged parents when it is suggested after 50 or 60 years of providing food, clothes, grooming, protection, and so forth that other arrangements need to be made to insure the well being of their loved one. Many aged parents are painfully aware that the majority of moderately or severely handicapped children and aged adults are inappropriately placed in institutions when they can't care for them. Opportunities for the severely physically disabled to live independently in group homes are virtually nonexistent. Also, Medicaid, the primary source of payment for disabled individuals in nursing homes, does not pay for any disabled person to reside in a nursing home unless there are compelling medical reasons. This holds true even if the individual has no other place to live. Until there are more community based, residential facilities for moderately or severely disabled people available, the last years for many will be spent in an institution. However, for families with large amounts of money and property held in trust, alternatives are available.

The need for financial and estate planning by these parents, is crucial in providing long term guaranteed care for their disabled dependent. Too often, this essential planning never takes place due to the tremendous societal barriers which must be overcome. Seeing the need to plan is the first hurdle. Decisions on living arrangements, medical care, determination of competency, whether guardianship is needed, the form of that guardianship if it is needed (over the person, the estate or both the person and the estate) and who shall be the guardian are only a few decisions that must be made.

The second hurdle to overcome, is to insure that the arrangements are fully understood by all parties. For example, in a guardianship relationship the dependent can lose the independent right to marry, to have and raise chidren, to spend earned income, to vote, to decide medical treatment, to choose living arrangements. Parents and disabled persons must understand the legal implications and consequences of all legal and financial planning. It is essential that the plan provides security for the person and that eligibility for government benefits is not inadvertently jeoparidized. Careful assessment, therefore, must be made of wills, trust instruments, guardianships, receipts of insurance proceeds and their impact on the maximization of government benefits.

The last hurdle, which is the most difficult to accomplish, is for the parents to communicate to their loved one, a sense of well being toward their future. My legacy for any severely disabled adult is that parents believe in their child's capabilities, respect his/her dignity and have confidence that he/she is capable of some measure of self-direction.

Conclusion

Throughout this paper I have attempted to highlight major points during a lifetime of living with disabilities. With that focus I chose the personal approach, "the human touch," to draw attention to the people whose abilities are inhibited by some arbitrary malfunction. Within that different body, the essence of life within demands the right to live that life to the fullest.

Disability is an irrational, irreconcilable fluke that occurs. But it happens everyday to many people. There is no natural or human law that decrees that any of us must or should live disabled, immobile, or misshapened. To ourselves we aren't demographic statistics. We aren't an unfortunate set of lamentable cause and effects from which to draw rational and objective conclusions. We are not separate and apart from anyone or anything else. We have pain but we also have pleasures. We have frustrations, disapointments but we also have victories. We struggle but we learn. Cerebral palsy. Autism. Mental or Sensory Disability. Whatever the disabling condition, the persepective is the same: Here is LIFE. Now, what can be done with it!

PART II: RESPONDING TO THE NEEDS OF FAMILIES

Chapter 1: Historical and Contemporary Responses to Disability

Chapter 2: The Development of Family Support Programs

Chapter 3: Statewide Family Support Programs: National Survey Results

HISTORICAL AND CONTEMPORARY RESPONSES TO DISABILITY

The occurrence of disability in society challenges both families and the greater community to provide adequate care for persons with disabilities. The efficiency and effectiveness of such care would be enhanced if there were a clear division of labor between families and publicly supported efforts (Caro, 1980). However, notions about the relative roles of society and families in providing care to persons with disabilities have fluctuated over the past several years.

Conflict in Roles Over Time

Demos (1983) notes that in any historical period the caregiving roles played by the greater society and by individual families are related to the interaction of five factors:

- The cultural context defines what segments of the population will be considered vulnerable or disadvantaged. For instance, Demos (1983) speculates that in earlier times the societal position held by elderly persons and persons with mild retardation was more favorable than today; life was less complex and more managable, and marginal employment was more easily obtained. As a result, these persons were, on the average, less vulnerable than persons today with similar disabilities.

- Demographic and biomedical considerations influence the numbers of persons with special needs present in any population. Given recent technological advances, we are growing older than ever and many children, who were at risk of dying just a few years ago, are surviving their early life crises. Moreover, just as the proportion of persons with disabilities is expanding within the population, the potential pool of family-based caretakers is shrinking due, in part, to increased numbers of women in the work force.

- Societal attitudes toward disability reflect the capacity and willingness of a given society to respond with care and concern to those in need.

- The magnitude of the organized societal response to disability reflects the role a society decides to play in the provision of care. Contemporary responses to disability suggest that government has taken a greater role than ever and has orchestrated development of a large human services industry.
- The family's composition, structure, strength and resources will, to some degree, influence the role it is willing to and capable of playing in caring for a person with disabilities.

Together, these factors dictate the division of labor between society and family concerning the provision of care to persons with disabilities at any point in time. Demos (1983) presents an historical profile of this tension in the United States and suggests that it encompasses three stages.

The Pre-modern Stage

This stage begins with the early settlements in America in the 17th century and extends into the early 19th century. During this stage emphasis was placed on the significant and dominant role of the family in shaping larger units of social organization and in providing care for all its members, including those with disabilities. Such care often involved the entire extended family for the lifetime of the person in need. The societal role was to oversee the general welfare of families. In extreme cases, civil authorities intervened to modify family behavior, punish individuals for failing to fulfill family obligations, or remove a person with disabilities from the family unit in favor of placement with another family. Clearly, this stage is dominated by an orientation to the acceptance of the role of the family as the primary caregiver since there were few (if any) public services.

The Institutional Stage

This stage begins with the 19th century and extends into the mid part of the 20th century. It is characterized by enormous growth in the number of institutional settings for persons with developmental disabilities and other vulnerable persons. The advent of such settings reflects a dramatic shift in the locus of responsibility for the care of persons with disabilities. Families were no longer automatically viewed as the caregiver of choice. Instead, despite the good intentions of many proponents of publicly supported services, these services often involved isolation of the person with disabilities from the family and the prevention of the "injudicious interference" of family members. Additionally, early in this period many believed that persons with disabilities should be segregated from the mainstream of society to protect these persons from the hardships of everyday life and to provide them with needed supervision and care. Later in the period, however, placing persons with disabilities into isolated settings was also premised on the belief that these persons were a menace to society (Wolfensberger, 1975).

To be sure, during this stage the great majority of persons with disabilities remained at home in the care of family members. What must be noted, however, is the increased role of society in providing care for persons with disabilities and the advent of the "residential assumption." That is, a person is assumed to require specialized residential services just because s/he has a developmental disability (Skarnulis, 1976). These changes in the balance of interests surrounding persons with disabilities resulted in an inconsistent and often conflicting division of labor between families and publicly sponsored service efforts. Whereas in the pre-modern stage families were viewed as competent and preferred caregivers, during this stage the capacity of families to provide suitable care was questioned and public services often were viewed as an adequate and preferred substitute to the family.

The Contemporary Stage

This stage begins in the mid-20th century and brings us to the present. It is characterized by a growing regard for the capacity of families to care for persons with disabilities, disillusionment with public institutional services, a more measured view of the role of professionals, and the advent of publicly financed services within the community. These occurrences reflect yet another shift in the locus of responsibility for care of persons with disabilities. During this stage, families are not expected to carry the full burden of care, nor are public services touted as an ample and preferred substitute to the family. Instead, families are increasingly viewed as capable caregivers whose efforts can be enhanced through publicly financed specialized assistance (e.g., parent education, financial support, and respite care).

This shift, however, has not yet been translated into effective policy. Though much contemporary policy encourages increased emphasis on maintaining persons with developmental disabilities within community-based alternatives and/or the natural family, these trends mask several counter-forces that could significantly undermine and inhibit the present initiative.

Present Barriers to Increased Support for Families

The numerous barriers confronting those committed to increasing the level of support accorded families who care for their members with disabilities can be sorted into four categories: attitudinal biases, demographic trends, uneven distribution of financial resources, and family-centered fiscal disincentives.

Attitudinal Biases

Three types of attitudinal barriers persist. First, professionals in the developmental disabilities field are far from reaching consensus over the role of the family in the provision of care. Some professionals discount the family's capacity for making sound decisions about the welfare of their child or adult with disabilities. The legitimacy of this claim is underscored by individual cases where parents decide against life saving or enhancing medical care for their offspring with disabilities, spurring calls from professionals to overturn parental decisions. Often, this issue is put before the courts in dramatic fashion where complex concepts pertaining to the rights of persons with disabilities, the bounds of parental autonomy, and the role of government in family affairs are discussed vigorously to no clear and final end (Skarnulis, 1974; Annas, 1979; Herr, 1984). Likewise, even where the medical status of the person with disabilities is not at stake, there is intermittent disagreement between professionals and parents concerning the most appropriate approach to habilitation. Some professionals go so far as to view the family as part of the problem, due to purported tendencies for overprotection and inherent attitudes that deter skill development (Crnic, Friedrich & Greenberg, 1983; Tapper, 1979). Given these considerations, professionals sometimes presume family incompetence and pursue out-of-home placement as a matter of course.

Second, society has not reached consensus over the public's role in private family affairs. This dilemma is both moral and political. Some believe, for instance, that parents themselves are responsible for any problems they encounter in bearing children and that the public should play a limited role in family affairs. This position suggests that public sector dollars should not be used to pay for care provided by families to their family member with disabilities. In contrast, others believe that the presence of a person with a disability in a family should result in increased public involvement because of the special needs of family caregivers and persons with disabilities. Such involvement includes provision of support services to help the family live a life that is as close to normal as possible.

The political reality is that far more persons with disabilities live at home with their families than in alternative residential arrangements but that the great majority of service dollars are spent on out-of-home options. Consequently, providing families with comprehensive support services would require either additional resources and/or re-allocation of existing funds. Given a scarcity of fiscal resources and significant pressure to maintain current allocation patterns, many are reluctant to support further development of family support programs. In fact, some claim that it makes little sense to allocate additional resources for a service (i.e., family care) that is already being provided at no public cost. On the other hand, proponents of family care argue that all parties would benefit if the family were provided with needed services and point out that even a small decrease in family efforts would confront legislators and taxpayers with enormous financial burdens. From this perspective, it makes programmatic and fiscal sense to promote rather than ignor family efforts.

Third, many families are themselves caught in a crossfire of conflicting interests and social role expectations (Farber, 1983).

On one hand, current lifestyles emphasize independence, self-actualization, and employment outside the home for women. Running counter to these values is a renewed interest in family-based care and a need to cope with the extraordinary demands such care entails. Consideration of these contradictory perpectives can create for many families an unsettling sense of ambivalence regarding their future and the future of their child.

Demographic Trends

In the future, persons with developmental disabilities may be increasingly vulnerable to out-of-home placement due to at least three population trends. First, in comparison to past census information, families, in general, are getting smaller; there are greater numbers of single parent families, and couples are having fewer children. This suggests that the family's capacity for providing long-term care may diminish because there will be fewer family members on which to rely. Supporting this speculation, Giele (1981) found that disproportionate numbers of elderly persons in institutions who need personal care are there only because they have no family with whom to live.

Second, the number of women entering the labor force is increasing (Keniston, 1977). This trend adversely affects the caregiving capacity of families because, in the United States, it is primarily women who have responsibility for providing such care. With this pool of caretakers shrinking, increasing numbers of persons with disabilities may be faced with out-of-home placement.

Finally, more and more persons are living in urban settings. In some ways this trend appears advantageous because, when compared to more rural settings, urban settings have more services and they are more accessible. For reasons that presently remain obscure, however, Perlman & Giele (1983) note that this trend can also result in decreasing occurrences of family-based care. For instance, Mahoney (1977) found that elderly persons were more likely to be assisted by relatives if they lived in rural or suburban settings than if they lived in urban settings.

Uneven Distribution of Financial Resources

Estimates suggest that the cost to taxpayers of the care of persons with developmental approaches three billion dollars annually (Braddock, Howes & Hemp, 1984). Sources of these dollars include federal programs such as Titles XIX and XX and Supplemental Security Income, as well as dollars raised through state and local taxes. The patterns of these expenditures, however, present a major obstacle to the promotion of family-based care (Tapper, 1979; Morell, 1983). This observation can be documented in two ways: 1) comparison of dollar amounts spent on institutional settings and community-based alternatives, and 2) analysis of the community services to which funds are allocated.

Several authors (e.g., Lakin et al., 1982; Copeland & Iverson, 1981; Braddock, et al., 1984) show through comparisons of the dollar amounts spent on residential care provided in institutional and community settings that significantly greater amounts are spent in institutional settings. These results are magnified further when it is considered that the majority of persons with developmental disabilities live in the community with their families or in supervised living arrangements (Moroney, 1981). Reasons for disproportionate expenditure patterns include: 1) regulations that encourage service planners to acquire funds designated for institutional and inpatient settings -- also known as the "co-location principle" (Noble, 1981), 2) the severity of the disabilities of persons in institutions compared to those living in the community (Bruininks, Hauber & Kudla, 1979), and 3) the pressure brought to bear on policy makers by special interest groups intent on maintaining institutional services (Blatt, 1981).

Recent information indicates that skewed funding patterns are being slowly corrected. Braddock et al. (1984) show that the ratio of dollars spent in institutional settings versus community settings was reduced from 3.46 to 1.0 in 1977 to an estimated 1.47 to 1.0 in 1984. Though these findings are encouraging, the disproportionate allocation of available funds remains a formidable impediment to an expanded and improved community-based service system.

Even the expenditure patterns within the community system are skewed. Examination of current spending reveals that a majority of community dollars are allocated to the development and maintenance of vocational training sites (e.g., sheltered workshops and activity centers), supervised living arrangements (e.g., group homes and apartment settings), and specialized evaluation and therapeutic clinics (Morell, 1983). Observing these trends, Tapper (1979) concludes that "as a matter of public policy, we grossly undersubsidize family care of the handicapped person, while at the same time lavishly support care outside the family setting" (p. 80).

Review of present policy suggests that community services are primarily designed to deliver habilitative services to individuals in settings external to the family rather than within the family unit (Morell, 1983). Though some persons with disabilities are helped by these policies, they do little to encourage or enhance family care.

Fiscal Disincentives

At least two fiscal disincentives to family-based care can be described. The most dramatic is the built-in institutional bias in Supplemental Security Income (SSI) and Medicaid policies. Under present deeming rules, the income and resources of parents is treated as though it were available to the SSI or Medicaid applicant or recipient as long as s/he is living with the family (and is under age 18). If the level of parent income and resouces surpasses the means income eligibility criteria, the person with disabilities does not qualify for SSI or Medicaid. In contrast, the parents' income and resources is not deemed to be available to the person with disabilities while s/he is residing in an out-of-home facility. Given these conditions, parents with children who have costly habilitative and/or medical needs may find out-of-home placement to be in the best interests of the child and family. This hypothetical analysis is bolstered by the highly publicized example of the Beckett family whose daughter with severe physical disabilities was placed in a hospital because funds for her care at home were not available.

A second disincentive to family-based care involves the "opportunity" costs to families of maintaining a member with disabilities at home. Boggs (1979) notes that parents often forego career advances in favor of providing habilitation within the family. For instance, a parent may reject a promotion if it means the family must move to an area lacking family support services or if one parent needs to assume increased responsibility for providing care to the family member with disabilities.

A similar consideration involves caretaking trends that show increased numbers of mothers entering the job market (Keniston, 1977). Mothers of children with disabilities may be inhibited from seeking employment due to the demands of providing care (Turnbull, Brotherson & Summer, 1985). As a result, these mothers may grow to resent their caretaking role and their families are denied access to a second income.

The opportunity costs associated with home-based care can lead many parents to conclude that the interests of the entire family can be best served through out-of-home placement. Consequently, a strong need exists to examine the effects of opportunity costs on the provision of family-based care and to develop policies that counter such disincentives.

Factors Spurring Increased Demand for Family Support

The impetus for family-based care stems from two major ideological tides. The first is "normalization." This notion began in Scandanavia (Nirje, 1969) and was later expanded upon in North America. The philosophy of normalization presumes that persons with developmental disabilities should be served within programs and residences that are as normal as possible and that they be taught skills necessary for life in the community (Wolfensberger, 1972).

The second major movement, which is also premised on the integration of persons with disabilities into community life, is "mainstreaming." Supporters of this concept advocate that children with disabilities be educated in public school classrooms, and placed in non-segregated or "mainstream" classrooms to the extent possible. This notion led directly to litigation to secure free and appropriate education for children with disabilities and ultimately to the passage of the Education for All Handicapped Children Act in 1975 (PL 94-142).

The emergence of these moral imperatives coincided with a variety of other events that both helped to clarify these ideas and shape their implementation. Several of these events are listed below:

- A growing body of literature that shows that persons with developmental disabilities have the ability to grow and to learn -- this reasearch was translated into the "developmental model";
- Mounting research on the debilitating effects of institutionalization and on the positive effects of home and community-based care (e.g., Close, 1977; Nihira, Meyers & Mink, 1983; Sokol-Kessler, Conroy, Feinstein, Lemanowicz & McGurrin, 1983; Schroeder & Henes, 1978; Conroy & Bradley, 1985);
- The ongoing improvement in instructional methodologies for persons with developmental disabilities of all ages to promote the acquisition, maintenance and generalization of skills (e.g., Engelmann and Carnine, 1982; Close, Irvin, Taylor and Agosta, 1981) and to remediate behavioral difficulties (e.g., Evans & Meyer, 1984; Hall & Hall, 1980);
- Increased evidence to show that parents can be taught specialized skills to meet the extraordinary needs of their developmentally children (e.g., Snell & Beckman-Brindley, 1984);
- The use of broad scale litigation -- especially in the federal courts -- to bring about improvements in institutional care and ultimately to secure services in the community in the "least restrictive setting" (Bradley & Clarke, 1976; Bradley, 1978; Conroy & Bradley, 1985);
- The momentum of the civil rights movement which highlighted the plight of blacks in the country and which also illuminated the discrimination inherent in the treatment of other minorities including developmentally disabled citizens (Browning, Rhoades & Crosson, 1980);
- The growing consumer movement resulting in the creation of politically active parent groups (e.g., the Association for Retarded Citizens) and self-advocacy organizations (Browning, Thorin & Rhoades, 1984).
- Increasing evidence that home and community-based care is more cost effective than institutional care (Ashbaugh and Allard, 1983; Ashbaugh, 1984).

All of these factors gave momentum to the principles of normalization and mainstreaming. Consequently, the emphasis on providing necessary services in the community has been clearly established within the service system as a guiding philosophy and factual reality (Lakin, Bruininks, Doth, Hill and Hauber, 1982).

The effects of this movement on state-wide service systems are well documented. Recent information indicates that the total population of state institutions for mentally retarded persons declined from about 195,000 in 1967 to just over 125,000 in 1981 and the number of persons receiving community residential services increased from 26,000 in 1967 to an estimated 90,000 by 1982 (Lakin, et al., 1982). Likewise, comparison of Children's Bureau Survey results of 1961 and 1977 reveals that the absolute number of children with handicaps (emotional disturbance, mental retardation and physical handicaps) receiving public school services has more than doubled (MacEachron and Krauss, 1983). Finally, many states now offer parents of persons with a developmental disability a variety of supportive services including case management, parent education, financial assistance, respite care and family therapy .

Present services, however, are not yet adequate. Many persons with developmental disabilities remain within settings that are too restrictive. Moreover, much still can be done to provide families with suitable types and amounts of specialized assistance.

The Current Challenge

Developing suitable policies to respond to the occurrence of disability is a complex undertaking burdened by historical, philosophical, methodological, and political considerations. To be sure, the increasing recognition of the crucial caretaking role families can and should play is encouraging. Proponents of family-based care, however, must counter the argument that care for an offspring is part of the moral responsibiltiy of the family and should therefore not be subsidized at all. The response is two-fold: 1) supports are necessary in order to make it possible for families to take advantage of the new (and many times expensive) technology that exists to assist persons with disabilities, and 2) supports are necessary because of the diminishing capacity of many families to provide care (e.g., because of the increasing number of single parent families, a reduction in the extended family, smaller number of children in the family who could contribute to care, etc.)

Based on a sound understanding of family needs, advocates of all kinds must convince policy makers that all concerned parties stand to benefit from the systematic application of family support services.

- The family benefits because of an enhanced capacity to provide care and an improved quality of life. Moreover, for some parents, receiving support services obviates any need for seeking alternative placement for their child or makes it possible for them to bring their child home from such placements;
- The person with developmental disabilities benefits because he or she is able to stay in a supportive home with more capable caregivers; and
- The state benefits because it has strengthened the family structure and may realize some cost savings due to a diminished need to fund expensive alternative residential options.

Moreover, arguments for family-based care should be translated into effective public policy that reflects a fundamental respect for the potential caregiving capacity of the family and that provides sufficient funding to guarantee an adequate array of services.

THE DEVELOPMENT OF FAMILY SUPPORT PROGRAMS

by

Colleen Wieck, Ph.D.

Murphy's Law[1] is as familiar to all of us as the Law of Gravity. Although human services are not governed by the same types of laws, rules, or principles as physical sciences, there are some common themes that do allow us to humorously reflect on current professional practice. In this paper, four major laws and seven corollaries patterned after Murphy's Law have been postulated to provide a framework for discussion of family support programs.

***Law # 1:* Human problems tend to be defined in terms that require professional solutions thus rendering them insoluble.**

This paper will provide definitive answers to the question, "what are family support services?" Definitions of "social support," "services," and "family" continue to be difficult for researchers, parents, and providers. The debate over programs and policies affecting families including family support programs, has been complicated by a lack of consensus regarding these definitions. The common stereotypic definition of family is "mother, father, and two children." The Bureau of Labor Statistics (1979) has published a cost of living index for census regions based on a hypothetical urban family of four consisting of "employed husband, age 38; a wife not employed outside the home; an eight year-old girl; and a 13-year-old boy" (p. 21). In contrast, the Census Bureau has abandoned the term family and adopted the term household to denote the range of living arrangements that currently exists.

---

[1] "Anything that can go wrong, will..."

Cobb (1976) defined social support as information exchanged at the interpersonal level which provides emotional support (care and love), esteem support (value as a person) and network support (mutual obligation and understanding). Support can occur in neighborhoods, in the family, and through self-help groups. Neighbors tend to provide short-term assistance. Families provide longer term support such as information, feedback, guidance, help, rest, identity, and an emotional base. Self-help groups form because of a mutual problem or situation.

Various taxonomies of family services have been offered. For example, Bates (1983) suggested that the term includes the following:

- Subsidized adoption;
- Direct subsidies to families;
- Respite care;
- Training; and
- Technical assistance.

Loop and Hitzing (1980) offer a more comprehensive and graphic representation of family services. (Figure 1).

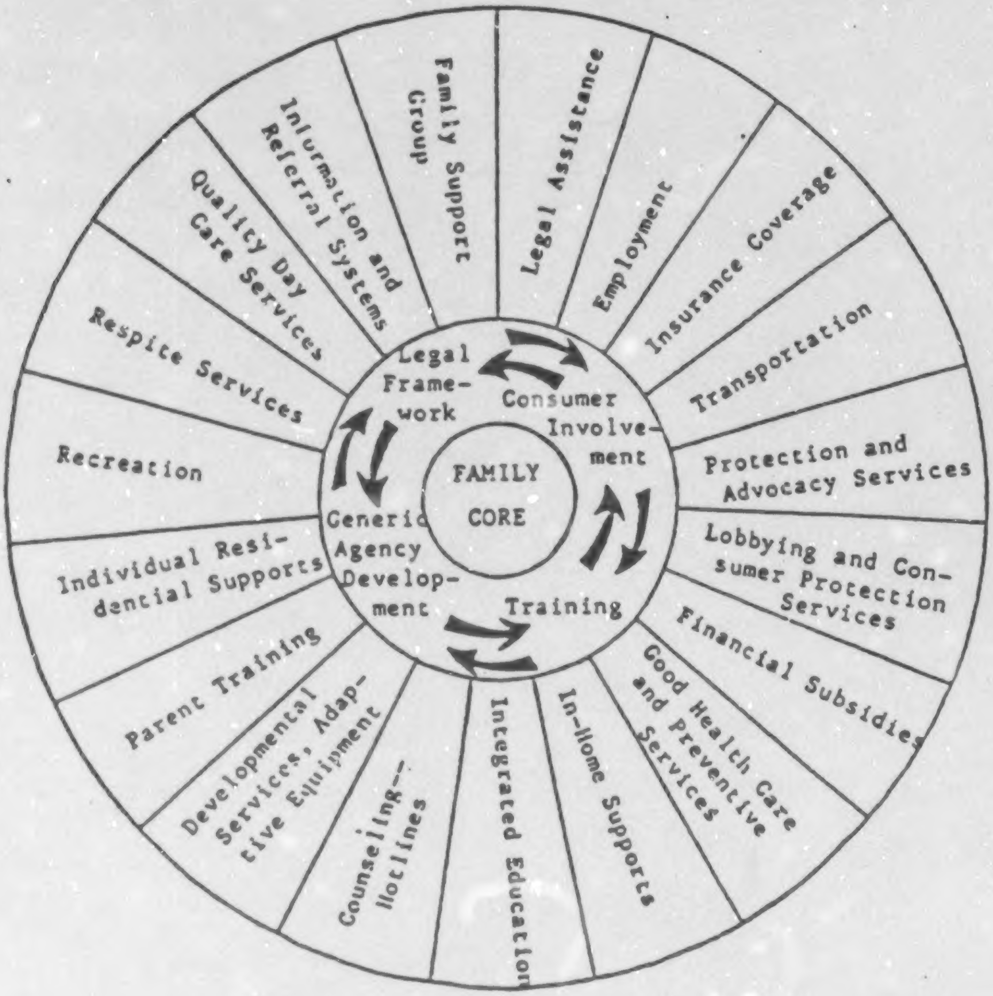

FAMILY CORE
Legal Framework
Consumer Involvement
Training
Generic Agency Development
Family Support Group
Legal Assistance
Employment
Insurance Coverage
Transportation
Protection and Advocacy Services
Lobbying and Consumer Protection Services
Financial Subsidies
Good Health Care and Preventive Services
In-Home Supports
Integrated Education
Counseling—Hotlines
Developmental Services, Adaptive Equipment
Parent Training
Individual Residential Supports
Recreation
Respite Services
Quality Day Care Services
Information and Referral Systems

Figure 1: Model Array of Family Resource Systems and Support Services for Children with Disabilities and their Families*

* Source: Loop and Hitzing, 1980

All families are currently feeling the impact of a combination of cultural, technological, psychological and demographic changes which have altered both the structure of the family and the roles filled by individual family members.

Structurally, the number and size of families have changed. The number of non-traditional households consisting of one person, more than one person not conventionally related, or single parents with children, especially female-headed households, has greatly increased. Smaller households have resulted from delays in marriage, high divorce rates, lower birth rates, and decreases in the number of multi-generational or "extended family" households. (Beck & Bradshaw, 1976; Bradbury, Bishop, Garfinkel, Middleton & Skidmore, 1977).

Family roles have changed with some family functions including care of older and younger family members, shifting outside the family or household unit. Women are continuing to participate in the work force in greater proportions, which affects the fecundity rate and increases demand for child care (McDonald & Nye, 1979).

The fundamental issue underlying family support programs is "who shall care for the members of the family, particularly those individuals with handicapping conditions?" In this context, it becomes especially important to examine the functions a family performs for its members, and to raise questions such as these:

- What are the conditions that allow one family to care for its handicapped member and force another to place the handicapped person out of the home?
- Why do family support services exist for mentally retarded persons but not for the families of persons with Alzheimer's disease, head trauma, or hundreds of other conditions that place chronic stress on families?
- Why do family support programs tend to focus on children and not young adults with disabilities who might be living in a household unit?

***LAW # 2:** If your handicapped child only needs 10 minutes of assistance, you can only receive 24 hours of care, usually out of the home.*

Reviews (McCubbin & Figley, 1983) of the traditional research in the area of family stress reveal emphasis on typical topics such as:

> Marriage, sexuality, parenthood;
> Divorce, step-relations;
> Careers, economic stress, retirement;
> Illness, death; and
> Natural disasters, war.

Usually, the topic of handicapped children is combined with illness.

A simple way of understanding family stress was first advanced by Hill (1949) and has been modified since:

A,B,C, -X.

A = the event and related hardship interacting with

B = the family's resources for meeting crisis interacting with

C = the definition the family makes of the event produces

X = the crisis.

The Philip Becker case provides an excellent example of the flexibility of this formula. This case ended up in the courts because the natural and adoptive families of a child with Down's Syndrome reached different decisions about whether the child should have heart surgery. In this case, the natural and adoptive families faced the same event (A) but had different resources (B) and definitions (C) of the crisis (X).

Another approach to assessing family crises comes from a set of eight questions developed by Lipman-Bluman (1975) who asked whether the crisis is:

1. Internal vs. external?
2. Pervasive vs. bounded?
3. Precipitous vs. gradual onset?
4. Intense vs. mild?
5. Transitory vs. chronic?
6. Random vs. expectable?
7. Natural vs. artificial generation?
8. Perceived insolvability vs. solvability?

There have been several studies on the effect of handicapped children on families, particularly on structure (Fotheringham & Creal, 1974; Beckman-Bell, 1981; Paul & Porter, 1981; Willer & Intagliata, 1984; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; Turnbull, Summers, & Brotherson, 1985), stress (Wikler, 1981; Shapiro, 1983), and coping (Wright, 1970; McDaniel, 1969; Neff & Weiss, 1965).

According to several investigators (Gruppo, 1978; Minde, Hackett, Killon, & Sliver, 1972; Heisler, 1972), families of handicapped children progress through stages similar to reaction to death: (1) shock, (2) disbelief, (3) rage, (4) guilt, (5) denial, and (6) adjustment.

The problems facing these parents of handicapped children are complex and call for ongoing support (Jefferson & Baker, 1964; Kendall & Calmann 1964; Younghusband, Birchall, Davie, & Kellmar, 1970). In a study published by McAndrew (1976), 116 mothers of handicapped children in Australia were interviewed. The strain on the Australian families for physical care of the children was considerable:

> The main brunt of the care was carried by the mother and probably accounts for the considerably bigger proportion of mothers compared with fathers who were in poor physical health (McAndrew, 1976, p. 244; Freedman, Fox-Kolenda, & Brown 1977).

The single largest expense was travel costs. Only a minority of the 116 families was experiencing financial problems. The Australian study noted that in addition to prompt accurate information families required the following types of assistance:

> Many of the families who used their car would be eligible for free travel vouchers from the State Health Department if they were able to make use of public transportation. A subsidy or tax deduction for travelling expenses would be a help to these parents. Financial assistance for home conversions was needed by a small number. A government subsidy would also assist these families. (Senate Standing Committee of Health and Welfare, 1971).

In addition to the parental view, siblings are beginning to speak out. A search of the literature revealed little work on siblings, although the need for professional aid for siblings has been noted by several authors (Carver, 1956; Caldwell & Guze, 1960; Graliker, Fishler, & Koch, 1962; Farber, 1963).

Gaiter (1984) summarized views of several adult siblings. As one sibling recounted:

> Sharing the pain, the anguish, the shame and the guilt of having a handicapped person is a family affair; it is not just a parents' affair (p. 18)

Of particular concern to siblings is the lifelong care and responsibilities for the handicapped person. Several siblings interviewed by Gaiter offered their own personal accounts about responsibilities:

> I may have passed up marriage a couple of times because of my sister (Rita Haahn, 52-year-old sister of Grace who is 48 and mentally retarded).
>
> I feel guilty for saying that I really didn't want the responsibility. Although I have an older brother, it is implied that I will inherit the care of our sister (a 58-year-old woman whose 53-year-old sister is mentally retarded. Their mother is 85 years old).

> Although programs are accessible to mentally retarded, few are accessible to autistic individuals. I feel very trapped because I know about all of these services and they're not interested in people like my brother (Daphne Greenberg, 21, whose brother is 23 years old).

Many siblings in the study expressed a desire to understand guardianship, placement, and how to deal with guilt.

As Farber (1979) observed, "Despite the vast increases in services to developmentally disabled people over the past 30 years, the major family problems remain the same." Loop and Hitzing (1980) admonish readers that "services focusing on supporting the family and the disabled child in the natural home have finished last when compared to other thrusts of deinstitutionalization."

***Corollary 2.1:* All parents should give up their own handicapped children, become foster parents for another handicapped child, and at night, shift the children back to the natural parents. In that way, families can receive needed services and keep their own children.**

Disabilities create financial hardships for families because of costs incurred for adaptive equipment, medication, therapies, and lost income due to caregiving responsibilities. Family subsidy can be helpful in meeting these costs (Turnbull and Turnbull, in press; Patterson and McCubbin, 1983; Boggs, 1979; Moroney, 1981). Traditionally, however, "resources are available once the handicapped child leaves home" (Horejsi, 1979). Moroney (1979) also observed that traditionally the state provides substitute care and not supplemental care.

Intertwined with the issue of family resources and capacity is the pattern of out-of-home placements. According to an early study of admission, Saenger (1960) identified two factors leading to out-of-home placement: (1) level of mental retardation and (2) behavior problems combined with families' capacity to cope. According to Lakin, Hill, Hauber, Bruininks, and Heal (1983), 11.9 percent admissions and 30.0 percent readmissions are related to family capabilities.

To prevent out-of-home placements, agencies must shift attention to the family. Lash (1983) explained:

> ...Agencies tend to focus exclusively on the needs of the developmentally disabled individual rather than looking at the entire family system . . . The first response of an agency must be, "How can we keep your family intact? (p. 19)

Paul and Porter (1981) argued for an even broader understanding of the family:

> An isolated view of persons with handicapping conditions can be superficial and inappropriate. No real understanding of the deficits, assets, and needs of the exceptional person can be achieved without comprehensive, in-depth attention to the values, expectations, resources, and circumstances of that person's social and physical environment. (p. 19)

There have been several demonstration projects that focus on home intervention to prevent placements. These projects have changed parents' attitudes toward institutionalization (Cianci, 1951, 1967); avoided large expenditures of money per client for out-of-home placements (Kinney, 1977, Pullo & Hahn, 1979); eliminated problem behaviors of children at home (O'Leary 1967; Allin and Allin, undated); and increased levels of confidence in handling children (Heifetz, 1977).

LAW # 3: Service systems will occasionally stumble over the truth, but most of the time, the system will move on quickly.

What are the goals of family support programs? The goals differ according to perspective. The government's perspective is to care for the child in the most cost-effective manner. The family's perspective is to receive necessary assistance to prevent out-of-home placement. For the person with a disability, the goal of family support must include the concept of maximizing potential.

Brown, Johnson, and Vernier (1983) have defined objectives for income support programs, some of which are also appropriate for family support:

1. Adequacy: The program must allow every recipient to receive sufficient help to meet minimum needs.
2. Horizontal Equity: Those families in similar circumstances should be treated similarly.
3. Vertical Equity: Families in different positions in the income distribution are treated differently according to financial position.
4. Target Efficiency: Programs should be planned and executed to meet the needs of those who are to be assisted.
5. Family Stability: Policies and benefits should encourage families to remain intact and avoid incentives toward family breakup.

There is little doubt that family support programs attempt to meet the objectives of adequacy, target efficiency, and family stability. The two objectives that result in problems in some states are vertical and horizontal equity.

VERTICAL EQUITY:	Those in greater need should benefit more than those in lesser need.
Point:	Why is family subsidy provided to "rich" families when "poor" families

are on a waiting list? Why isn't this program based on income?

Counterpoint: A "rich" family can place their handicapped child out of the home as easily as a "poor" family. The purpose is to prevent out-of-home placements regardless of income.

HORIZONTAL EQUITY: Those with equivalent needs should receive equal benefits.

Existing Problems: Some groups of needy families are excluded, particularly if the subsidy is designated for children with the most severe handicaps.

Some groups receive favorable treatment over others (parents of mentally retarded children compared to parents of children with cerebral palsy, autism, head trauma, and others).

Geographic inequities exist in the United States since only about 25 states provide family support. In addition, states vary in how programs are operated, the level of benefits, and the standards of eligibility for benefits.

There are several questions that remain unanswered regarding the effectiveness of family support programs in meeting service goals and objectives. These areas include:

Is there any evidence to suggest that family support programs negatively affect the family structure and function?

Should family support help those families already receiving income support, or should family support include middle class families?

Should family support be an entitlement program assuring benefits to all who meet the established criteria?

Should family support be a needs-based, limited service with benefits rationed to those among the eligible who are deemed most in need according to some defined criteria?

Corollary 3.1: Even after refined diagnosis, there is no change in treatment.

Turnbull, Summers, and Brotherson (in press) suggest the family has several functions: economic, physical caregiving, rest and recuperation, socialization, self-definition, affection, guidance, education, and vocational.

The range, utility, and benefits of family care can be expressed very simply:

> Development at home is better (Poznanksi, 1973);
>
> A family provides social development and emotional security (Schiel, 1976);
>
> Disabled children have a right to be a member of a family (Vitello, 1976); and
>
> Habilitative family care includes care, training, and supervision of the developmentally disabled person in a planful manner (Horejsi, 1979).

In addition, a child with a disability may be in a family home because it is the least restrictive environment. As Trace and Davis (undated) have operationalized the term least restrictive environment:

> When there is a need for intervention, the intervention should be no more drastic than that required to meet the needs of the disabled person.

To test whether family care is restrictive, both liberty and developmental potential must be examined. The Trace and Davis approach assesses whether the person with a disability is competent and is prevented from performing the activity in the setting. There are three basic reasons for overrestrictiveness. First, a caregiver performs the activity for the individual. Second, a caregiver prevents the individual from doing the activity. And third, the caregiver may require additional training that is unnecessary for the consumer.

***Corollary 3.2:* In order to have a family support program, you must first spend billions of dollars on bricks and mortar in remote rural areas so that you can rediscover the efficiency of the familiy.**

Over 100 years ago, there were fewer than 2,500 mentally retarded people in state institutions in the United States. The number increased to 195,000 in 1967 and has declined to 130,000 in 1982. In combination with the decline of state institutions, there has been a large increase in the number of community/residential alternatives. From 1977 to 1982, the number increased from 4,427 to over 15,000 (Hill & Lakin, 1984).

During the same time period, the cost of providing state institution services has continued to increase dramatically. In 1915, the annual per capita cost per client was $45,000. In 1916, Cornell observed that until the cost of institutions was reduced to under $100, the public would object to segregation on the ground of expense (Wieck, 1980). In 1970, Baumeister said that "more money is spent on the five percent [of mentally retarded people who are institutionalized than on the 95 percent] who are not [in institutions]" (p. 22). Scheerenberger (1980) estimated that during the decade of the 1970s, the per diem rate increased over 450 percent.

Most recently, Braddock (1984) analyzed federal and state expenditures for institutions and community services. Between 1977 and 1984, the United States government spent $13 billion on ICF-MR (Intermediate Care Facilities for Mentally Retarded) reimbursement. Of that amount, 82 percent was spent on state institutions and 18 percent on community facilities. According to very rough calculations based on the summary of family support programs provided in a subsequent section (Part II; Chapter 3), about $50 million was spent in 1983-1984 on family support programs in those 22 states with the most extensive programs (though several other states have family support initiatives in place, those other programs are relatively modest and would not add much to this dollar estimate). Compared to the billions spent on out-of-home placements, less that one percent of funding is designated for family support.

In 1982, there were over 60,000 children (birth to 21 years old) in out-of-home placements which is a reduction of 30,000 children since 1977. The reduction is attributed to aging, reduced admissions, and transfers. Moreover, the recent inception of several family support programs may have had some effect.

In comparing the average daily costs of various options in 1982, there is a wide range of cost:

Type of Placement	Cost
Family support	$8.33 (est.)
Board and room	$15.97
Foster care	$16.15
Personal care	$17.05
Semi-independent living	$27.50
Group home (1 to 15)	$38.31
Group home (16 or more)	$45.15
Nursing home	$49.81
Public group homes (16 or more)	$85.84
Average out-of-home placement	$61.89

The rising cost of residential placements has intensified the search for alternatives to out-of-home placements and the emphasis on families. While some argue that by focusing on cost, attention is shifted from civil rights and humanitarian concerns, economics cannot be dismissed.

Corollary 3.3: The best family subsidy program works only one-fourth as well as the administrator says it does.

Of specific concern to this paper is the utility of family support programs. Since 1976, Minnesota has had a family subsidy program for children who are Minnesota residents and living at home or residing in a state hospital or in a licensed community residential facility for the mentally retarded who, under this program, would return to their own home.

Priority is given to families of severely and multiply handicapped children who are experiencing a high degree of family stress and show the greatest potential for benefiting from the program.

The program provides grants to parent(s) in an amount equal to the direct cost of the services outlined in a service agreement. Grants are made up to a maximum of $250 per month per family to assist in paying for diagnostic assessments, homemaker services, training expenses including specialized equipment, visiting nurses' or other pertinent therapists' costs, preschool program costs, related transportation expenses, and parental relief or child care costs.

In 1983, the Minnesota Developmental Disabilities Council sponsored an evaluation of the family subsidy program. A sample of 70 families was selected, and 38 families participated in the evaluation. The families' overall responses were very positive, with thirty-seven families (97%) reporting that the program is of "great or very great help" to them, and only one family (3%) rating the program as being of "some help." A majority of the respondents felt that the subsidy was of great or very great help in the following activities:

> . . . purchasing special items needed by the child (n=36, 95 percent); attending to the needs of the developmentally disabled child (n=35, 92 percent); purchasing babysitter services or respite care (n=27, 71 percent); doing things outside the home, such as going to movies or taking walks (n=23, 61 percent); doing things with other children in the family and their spouse (n=22, 58 percent); and attending to the needs of other family members (n=21, 55 percent). (p. 6)

Comparison of respondents' perceptions of their situation before and after program participation revealed a marked improvement in their abilities to purchase special items and services for the disabled child and to attend to the needs of the disabled child and other family members.

While the families reported that the program enables them to function better and to care for their disabled child at home, the subsidy does not cover all of the expenses entailed in the child's care. Almost two-thirds of the families (n=24) reported additional expenses in the categories covered by the subsidy.

Thirty-four families (89 percent) said they thought the program should be expanded to include young adults. One respondent, however, felt the program should not be expanded while there are families with young children waiting to be served by the program.

Respondents offered several suggestions to improve the application process, increase the program's publicity, and improve the benefits provided. The suggestions included:

- Yearly applications rather than every six months;
- Optional phone renewal of the applications;
- Education of local social and health services staffs about the program;
- Use parents to publicize the program;
- Increase benefits for families with greater needs; and
- Increase allowed benefits to include long distance medical calls and emergency respite care. (Minnesota Developmental Disabilities Program, 1983a).

Florida has conducted two evaluations of their family support program. Initial problems were noted with staffing and reimbursement schedule. In the second evaluation, the payment method remained a problem to families (Bates, 1983).

In an attempt to define a national policy on families that could alleviate such problems as juvenile crime, teenage pregnancy, suicide among youth, child abuse, and domestic violence, President Carter initiated a series of state and national White House Conferences on the Family (Dworkin, 1978). There are, however, a number of problems in framing a national policy on the family. According to McDonald and Nye (1979), these problems include (1) definitions, (2) unexpected consequences of government actions, and (3) tax laws. There is also growing interest in defining the domain of rights separate from government interventions. The rights of families were described in a special issue of the "Harvard Law Review" (1980):

- Form a family and marry;
- Make childbearing decisions;
- Maintain custody of children; and
- Bring up children while recognizing child's constitutional rights.

Currently, there are two basic schools of thought regarding the balance between family autonomy and dependence on governmental assistance. One group of policy analysts maintain that a family is the responsibility of its members, not government (Berger & Neuhaus, 1977). They argue for less government intervention and increased reliance on families, neighborhoods, churches, and voluntary associations to address family issues. To this group the specter of socialism rises when any large outlay of funds to serve more families is discussed. According to this point of view, family support programs can be perceived as running counter to a basic tenet of capitalism -- that those who do not participate in economic development should not receive benefits. Some authors with this group (Ozawa, 1982) argue that serving more families would be an uneconomical use of resources and that other programs should be made more efficient to prevent out-of-home placements.

On the other side, there are authors who argue that helping families preserves human dignity and that there should be more government assistance in the area of income and jobs (Featherstone, 1979).

The controversy over government assistance to families extends beyond questions of whether and how much government should assist families to questions about limited resources and complicated moral dilemmas.

As Moroney (1979, 1981) has described in several publications, there is competition among several groups (elderly, mentally ill, mentally retarded, chemically dependent, children and others) for scarce resources.

The Baby Doe cases have raised several questions about a society that wants children's lives saved but may not be willing to support the child after discharge from the hospital. A _New York Times_ editorial (1984) pursued the questions of support:

> A society that understandably wants doubtful cases resolved on the side of life also has an obligation to those for whom such a life may be extremely painful: the infants and their immediate families. Pending amendments in Congress ask for study of the best ways to provide federal financial support for the treatment of disabled infants. But who will pay for an adequate level of _continuing_ care?

In reviewing the policy biases that remain against family support, one of the largest concerns is that state legislators are torn between the desire of providing for needy persons and the fear of creating uncontrolled programs. With family support programs, legislators are faced with several questions:

- Who should receive benefits?
- Should benefits be related to characteristics of the family or level of functioning of the child with a disability?
- Can benefits be coordinated with tax treatment or tax policy?
- Can family support benefits be coordinated with other income maintenance programs?

__LAW # 4__: Family support programs that require no professional training today will soon require certification, accreditation, annual national surveys, federal grants, public announcements, and a history by Richard Scheerenberger.

There is a predictable and unfortunate course that most human service programs such as state institutions, community residential facilities, day programs, and waivered services tend to follow. The tendency is to: 1) professionalize a program; 2) form a national organization that can splinter the Association for Retarded Citizens (ARC) even further; and 3) require national surveys so that counts can be tabulated and progress can be proclaimed. The ultimate criterion is, of course, an historical account by Richard Scheerenberger published by the American Association on Mental Deficiency (AAMD). Federal involvement comes in the form of demonstration grants which usually results in dissemination of voluminous reports and taped public service announcements applicable only to the demonstration project. Can we prevent family support programs from becoming professionalized?

__Corollary 4.1__: We can predict the number of family support programs. In even-numbered years, there will be an even number of states with programs. Given the current rate of development, by the year 2004, all states will have family support programs.

Based on the careful work of Bates (1983) at the Wisconsin Developmental Disabilities Council, we have an annual status report on the number and type of family support programs. Some simple estimates suggest that while family support programs are expanding, the rate of increase does not match the need of families. It seems absolutely essential to move away from the experimental or demonstration approach to a larger-based adoption of programs. The Medicaid community services waiver may be one alternative to the limited state-supported family support program. Further analyses will be needed to determine the extent of family support in the state because of the waiver.

Several authors have described the empowerment of families because of legislation and litigation. Institutions and segregated placements are no longer accepted remedies given changes in philosophy, P.L. 94-142, and judicial principles such as least restrictive environments (Paul & Porter, 1981; Beckman-Bell, 1981; Turnbull, 1981; Turnbull & Strickland, 1981).

The Minnesota Developmental Disabilities Council published two policy briefing documents in 1983 and 1984. In 1983, two paradigms were described: the consumer-powered system and the resource-powered system. In a resource-powered system, services are based on funding availability and a general estimate of need. Clients are placed depending on availability of slots with clients fitting the system. The result is inappropriate placements.

In a consumer-powered system, the client's needs are assessed, and case managers function as brokers, advocates, and creators of services to meet individual needs. Evaluation is systematic and based on outcomes.

The resource-powered system is common in a state where individual needs must contend with perverse fiscal incentives that favor placement in the most restrictive and most expensive settings. In Minnesota, Intermediate Care Facilities for Mentally Retarded (ICF-MRs) are the most common residential option. While $200 million is spent on ICF-MR facilities, less than $1 million is earmarked for family support.

In 1984, the Minnesota Developmental Disabilities Council pursued a policy agenda including several goals in the area of supporting families:

> Increasingly, public policy supports the idea that the place for people with disabilities to build their futures is in the community. (p. 7)

A vision of the future must involve supporting communities to act responsibly, to be competent, and to recognize and support the citizenship of people with disabilities. This vision of a responsive community includes:

> A community where children can grow up as members of families;
>
> A community where children and adults can be part of loving and caring relationships;
>
> A community where all children can learn together and from each other; and
>
> A community where people can turn not only to community services but their friends and neighbors for support.

At the federal level, the President could proclaim a new initiative to move the 13,000 children now residing in state institutions to less restrictive settings. The approximate cost of out-of-home placement can be 8 to 16 times greater than family support programs. While some children may be in appropriate placements, others should be transferred without dumping and without hardship to families.

The federal government could also consider helping children through an allowance program regardless of parental status or family income. At this time, 69 nations (28 European, 24 African, 2 Asian, 3 Middle East, 10 South American, Australia, and New Zealand) have family allowance programs. In Bolivia, there is a housing allowance, birth grant, nursing allowance, burial allowance, and monthly cash payments. The positive outcome of a children's allowance program is elimination of current income maintenance programs that regulate and coerce parents. If all children receive an allowance, there is no stigma because of handicapping condition. Some analysts oppose children's allowances for several reasons:

> First, children's allowances, like any governmental intervention in economic activities, would impede free competition and eventually result in uneconomic utilization of resources. Second, children's allowances would conflict with the basic principles of the capitalistic system, in which all are to be rewarded, not according to their needs but according to their contribution to the general economy. Third, children's allowances would create a powerful drive toward socialism. Fourth, if financed by progressive taxation, children's allowances would reduce the capacity and the incentive for the rich to save and invest. This in turn would discourage innovation and invention, which are real sources of economic progress, and consequently, could adversely affect standards of living. Fifth, for advance in economy, human beings shold not have excessive security but a balance between reasonable security and resonable exposure to the risks in life. (Ozawa, 1982, p. 206)

On the other hand, Thorsson (1968) argued that children's allowances are an:

> . . . ultimate right of every child irrespective of background, place of living, income of parents, and so on, to be welcomed, to have an economically and socially secure childhood and adolescence, with equal opportunities for a good start in life and equal access to educational opportunities in order to develop his/her full potentialities. (p. 14)

Finally, initiatives that states should consider include:

- A checkoff on tax returns to "Save the Children" similar to checkoffs for political parties;
- Adoption of a version of S. 2053[1] (The "Community and Family Living Amendments of 1983") at a state level to place emphasis on smaller living arrangements and alternatives to institutions; and
- Fund Individual Service Plans rather than buildings and programs.

---

[1] S. 2053 proposed to shift the share of Federal Medicaid funds from long-term institutional arrangements to community-based, integrated, family scale environments. Recently, S. 2053 has been revised somewhat and referred to as the Community and Family Living Amendments of 1985 (S. 783).

STATEWIDE FAMILY SUPPORT PROGRAMS: NATIONAL SURVEY RESULTS

by

John Agosta, Ph.D., Debbie Jennings and Valerie Bradley

Families of persons with developmental disabilities face a variety of dilemmas and choices regarding the provision of long term care. Tradtionally, such families are accorded few, if any, services to support their efforts and often are encouraged to seek residential placement for their child with disabilities away from the family home (Perlman, 1983; Skarnulis, 1976; Bruininks & Krantz, 1979). Recent policy initiatives, however, have focused increasingly on establishing statewide programs to provide systematic support to families with developmentally disabled members (Bates, 1984; Bird, 1984; Michigan Association of Community Mental Health Boards, 1983; Nebraska Legislative and Advocacy Committes, 1980).

The fundamental goals of these programs are to strengthen the family's capactiy to provide care, prevent undue out-of-home placement, and promote development of a family life that is as close as possible to that experienced by families without members with disabilities. To acquire an improved understanding of this movement, the Human Services Research Institute and the National Association of State Mental Retardation Program Directors undertook a national survey of existing statewide family support programs. The purpose of this paper is to report the results of that survey.

Method

Approach Taken

Information was solicited from officials in the 50 states during a survey period beginning in November, 1983 and continuing through

November, 1984. A family support program was defined as a statewide initiative, funded and monitored through the administrative auspices of the state, to provide systematic support to families with members with developmental disabilities.

The survey process included three steps. First, "survey contact forms" were sent to state directors of services for persons with developmental disabilities to determine the presence or absence of various family support services and to obtain the names of other knowledgeable persons in the state. Second, to gather information in greater detail, 57 "interview guides" were distributed to persons identified through the initial contact forms. These guides solicited specific information regarding program characteristics, funding levels, program effects, and factors influencing program growth. Finally, follow-up telephone inquiries to persons in several states were undertaken to help clarify information collected previously.

Response Rate and Limitations

Information was collected from all 50 states. Survey results, however, must be considered in light of three limitations that became apparent during the course of the survey. The first is related to the absence of a well articulated and widely accepted definition of "family support." Paul Castellani (See Part III; Chapter 1) notes that the few available studies that deal with definitional issues focus mostly on taxonomies of provided services (e.g., respite care, home barrier removal) and that these taxonomies are not always compatible. Such definitional ambiguity complicates the matter of surveying "family support programs" since survey respondents do not necessarily share a common frame of reference. Thus, services listed under a "family support" rubric in one state may not be listed as such in other states.

Second, discussions with numerous state officials revealed that several states operate a variety of family support services but that various services may be administerd by different state level divisions. Thus, directors of developmental disabilities programs may have neglected to mention relevant services administered by other state level agencies.

Third, the comprehensiveness of the responses secured varied considerably. Some state officials cooperated fully and forwarded much useful information. In contrast, others provided little information. As a result, survey results may underestimate the family support efforts in some states.

Results

Service Types by State

All states but Oklahoma indicated the presence of some type of family support program. These programs were sorted into three administrative categories. First, Cash Assistance Programs provide money to families to offset the costs of habilitative materials or services. In such programs, families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for costs of care incurred. Second, Supportive Programs provide families free inkind habilitative materials or services. In these programs states fund various agencies which in turn provide specified services. Finally, Combination Programs offer families both cash assistance and inkind support services.

Table 1 displays the 49 states that report the existance of a family support program according to the administrative category that

Table 1: States Offering Family Support Services by Primary Administrative Category

---

Cash Assistance Programs

1. Connecticut
2. Idaho
3. Illinois*
4. Indiana
5. Louisiana
6. Minnesota
7. Nevada
8. North Dakota
9. South Carolina

Supportive Service Programs

1. Alabama
2. Alaska
3. Arizona
4. Arkansas
5. California
6. Colorado
7. Delaware
8. Georgia
9. Hawaii
10. Iowa**
11. Kansas
12. Kentucky
13. Maine
14. Massachusetts
15. Mississippi
16. Missouri
17. New Hampshire
18. New Jersey
19. New Mexico
20. New York
21. North Carolina
22. Ohio
23. Oregon
24. Pennsylvania
25. South Dakota
26. Tennessee
27. Texas
28. Utah
29. Vermont
30. Virginia
31. Washington
32. West Virginia
33. Wyoming

Combination Programs

1. Florida
2. Maryland
3. Michigan
4. Montana
5. Nebraska
6. Rhode Island
7. Wisconsin

---

* The Illinois state legislature has ratified a bill to permit operation of a cash assistance program but has not yet appropriated funding for the approved program.

** The Iowa State Developmental Disabilities Council had funded a cash assistance program since 1981 but terminated funding on 9/30/84. The state does provide certain supportive services.

best exemplifies each state's support system. Review of this table shows that nine states operate cash programs primarily. 33 provide in-kind supportive services, and seven operate combination programs.

These findings, however, must be considered in light of two factors. First, though nearly all states report the presence of a family support program, fewer than 25 have developed "extensive" initiatives that are well coordinated and available statewide. Many other states recognize the importance of supporting family efforts but offer few services to few families or administer programs in restricted areas.

Second, statewide initiatives often are complemented by services made available through sources other than the state mental retardation or developmental disabilities service system. Examples include programs sponsored by:

- the public schools. Due in great part to the Education for all Handicapped Children Act (Public Law 94-142), public schools in all 50 states offer special education to children and young adults with developmental disabilities. Though the age range served varies somewhat by state, about four million persons with disabilities received special education services during the 1982-83 school year (Division of Education Services, 1984). In addition, some school districts offer outreach services to the families of these persons (e.g., parent education). The positive impacts of these services on persons with disabilities and on the family's capacity to provide care cannot be overlooked;

- advocacy organizations. Numerous national and locally based advocacy organizations sponsor a variety of services to family members (e.g, information and referral, parent education, mutual support groups) and to persons with disabilities (e.g., recreational activities). Some of these organizations serve persons with a specific type of disability (e.g., downs syndrome, autism, prader-willi syndrome), while others are not so specialized (e.g., American Coalition of Citizens with Disabilities) (See Office of Information and Resources for the Handicapped, 1982);

- specialized family service agencies. These organizations offer one or more useful services to family members or persons with disabilities and often charge a fee. For instance, these agencies may provide parents assistance with financial planning (see Part III; Chapter 2), instruction on how to be an effective participant in the service planning process, or access to special toy libraries or "lekoteks" (ALMA Matters, 1985) and may offer persons with disabilities specialized services as well (e.g., structured vacations away from home);

- university programs. These programs offer a range of services for persons with disabilities and their families. Often, they operate as a federally financed demonstration project and/or through a University Affiliated Facility (UAF) or Project (UAP); and
- private sector intiatives. These programs are provided by employers for their workers or private businesses not typically structured to provide human services (See Part III; Chapter 4).

Thus, when considering the potential utility of any state's family support system, the presence of these other services should not be discounted.

Analysis of Programs in 22 States

Though numerous states report the existance of a family support program, data presented in this section are confined to a sample of 22 states with the most "extensive" systems. Tables 2, 3 and 4 display information on these 22 states along six dimensions with each table displaying states in the same primary administrative category. When viewed simultaneously, these tables reveal considerable variance in the following areas:

Date Initiated. Pennnsylvania was the first state to initiate a family support program of any kind (1972) and South Carolina was the first to initiate a cash assistance program (1974). Most programs (66%), however, were begun since 1980.

Eligiblity Criteria. All states impose eligibility criteria of some kind but these criteria vary by state and can be sorted into three informational categories. The first pertains to client characteristics. In all states a family must be providing care to a person with a developmental disability but states further restrict

Table 2: Eight Cash Assistance Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Connecticut	1981	Cash Program	$2,000 per year	15	$23,106	developmental disabilities	sliding scale based on income and family size; no other public assistance received	at risk of out-of-home placement or returning from such placement
Idaho	1981	Cash Program	$250.00 per month ($3,000 per year)	138	$47,000	developmental disabilities; under age 21		priority to those at risk out-of-home placement or returning from such placement
Indiana	1982	Cash Program	Determined by casemanger, maximum of $500 per month for respite	191	$185,000 (FY 1985)	developmental disabilities		priority to those at risk of out-of-home placement
Louisiana	1983	Cash Program	$375.00 per month ($4,500 per year)	25	$112,500	mental retardation		
Minnesota	1975	Cash Program	$250.00 per month (3,000 per year)	190	$525,000	primary diagnosis of mental retardation; under age 18; priority to severest disability	priority to greatest resource needs	
Nevada	1981	Cash Program	$286.00 per month ($3,432 per year)	67	$110,000	profound mental retardation	insufficient income to cover costs of care; sliding scale based on family income & size	
North Dakota	1981	Cash Program	$15/week for basic care; $35/week for services/ treatment ($2,600 per year)	200	$200,000 (3 year pilot)	developmental disabilities; under age 21		
South Carolina	1974	Cash Program	150.00 per month ($1,800 per year)	15	$23,000	mental retardation	insufficient income to cover costs of care	

Table 3: Seven Support Services Programs by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
California	1982	Support Services	varies by individual but no set limit	35,000 (all ages)	$5,100,000 (for persons under 18 years)	developmental disabilities		
New Jersey	1980	Support Services	No limit on intervention services but only 30 days respite/year	850	$967,187	mental retardation	means income eligibility standard	
Ohio	1983	Support Services	$2,500 per year	Program initiated 4-1-84	$700,000	developmental disabilities		
Oregon	1983	Support Services	No set limit	about 1,000	$3,100,000	developmental disabilities; under age 6		
Pennsylvania	1972	Support Services	No set limit	11,548	$3,487,278	mental retardation		
Vermont	1978	Support Services	$990.00 per year	260	$381,279	mental retardation		
Washington	1977	Support Services	$750.00 per year	800	$2,154,000	developmental disabilities		

Table 4: Seven Combination Programs by Six Areas of Information

TATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
da	1978	Combination Program	Based on need; no maximum	8,229 (210 in Cash Program)	$21,000,000 (1,200,000 for Cash Program)	developmental disabilities		at risk of out-of home placement if services not receiv
and	1984	Combination Program	No set limit; based on need within reason	103	$197,000	developmental disabilities under age 22		at risk of an out-of-home placeme
gan	1984	Cash Program	$225.00 per month ($2,700 per year)	Estimated at 2,000	$5,700,000 (est. FY 1985)	severe mental or multiple impairment, autism; under age 18	family taxable income for year preceding application cannot exceed $60,000	
	1983	Support Services	No set limit; limited by budget	355	$495,000	developmental disabilities		
na	1975	Combination Program	$1,385 per year	600	$1,125,000	No set priority but preference to young and severe disabilities		
ska	1982	Combination Program	$300.00 per month averaged over one year	115	$200,000	developmental disabilities	insufficient income to cover costs of care	
e Island	1981	Combination Program	$60/week for basic care, $15/week for training ($3,900/year)	65	$256,000	mental retardation; mental illness; chronic impairments		resident of state residential facili for 90 days to rece a cash subsidy
onsin	1984	Combination but varies across the state	$3,000 per year	197	$125,000	severe disabilities; children	no access to sufficient funds to cover costs of care	at risk of an out-o home placement or returning home fro such placement

those who qualify based on such factors as disability type (eight states), age (six states), or severity of disability (five states).

A second category pertains to family resources. In seven states, service availability or cost to the consumer is made contingent on some type of means test, such as a sliding scale, or on some judgement of the family's capacity to cover the costs of care.

The third information category involves consideration of the placement status of the person with disabilities. Six states prefer that the person be at risk of an out-of-home placement, while three states require that the person must be returning home from such placement. Rhode Island stipulates that to receive a cash subsidy, the family member with disabilities must have been a resident of a state residential facility for 90 days.

Client/Family Expense Limits. Most states (16) set some specific limit on the amount of money that can be expended annually on individual families. Though six states indicate that no such limits exist, officials in these states readily admit that the total program budget naturally restricts the amount that can be spent and that costs must be held "within reason."

Numbers of Clients/Families Served. For the most part, states with the greatest population densities tend to serve more families than states of lesser population density. California serves the most families by far (35,000) while Pennsylvania administers the second largest program (13,000). Connecticut and South Carloina operate the smallest programs (15 families). The total number of persons served by the programs profiled is 61,963 (this total excludes those served in Ohio because such figures were unavailable at the time of the survey).

This figure is considered by many to be unsatisfactorily low when it is considered that: 1) the overwhelming majority of persons with developmental disabilities live at home with their natural families (Perlman, 1983; Maroney, 1981; Bruininks, 1979), and 2) 243,669 persons with developmental disabilities are served in out-of-home residential alternatives, including institutions and community-based arrangements (Hauber, Bruininks, Hill, Lakin & White, 1982).

Appropriation Levels. As expected, the amount of funds appropriated varies with the number of clients/families served. Appropriation levels ranged from $21,000,000 for a combination program in Florida serving 8,229 families to $23,000 for cash assistance programs serving 15 families in both Connecticut and South Carolina. Moreover, survey findings show that cash programs are generally funded at lower levels than either support or combination programs with combination programs generally receiving the most fiscal support.

Table 5 lists all 22 states and illustrates what services are permissible besides case management. In addition to these services, at least 11 states have provisions for families to acquire services that are not regularly permitted. For example, families in Pennsylvania can present extaordinary service needs to local review boards. Though state guidelines influence decisions, these boards are at some liberty to ratify the provision of unique services. Likewise, Michigan will allow any service the family views as contributing to its capacity to provide care.

Review of Table 5, however, suggests significant variance among states regarding the range of services offered. The services noted most frequently are temporary relief or respite care (21 states) and

Table 5: Permissible Services in 22 Family Support Programs

SERVICES	STATES																						TOTAL
	CA	CT	FL	ID	IN	LA	MD	MI	MN	MT	NB	NV	NJ	ND	OH	OR	PA	RI	SC	VT	WA	WI	
laptive Equipment	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X			X	X	X	X	X	20
lucational or Therapeutic ervices for disabled person examples include physical, peech or vocational therapy, ehavior management)	X	X	X	X		X	X	X	X	X			X	X		X	X	X	X	X	X		17
ansportation	X	X	X	X	X		X	X	X	X	X	X		X		X			X		X	X	16
dical or Dental Services	X	X	X	X	X	X	X	X	X		X			X				X	X			X	14
using Modifications	X		X	X		X	X	X	X		X			X	X		X	X	X			X	14
ecial Clothing	X	X	X	X				X	X			X		X						X		X	10
et or Nutrition Services			X	X		X	X	X	X			X		X	X							X	10
agnosis and Assessment	X		X	X				X	X	X	X			X								X	9
dications		X	X			X	X	X	X		X								X				8
me Health Care				X		X	X	X			X		X	X									7
rsonal or Attendant Care	X					X	X	X			X												5
creational Services			X	X										X			X					X	5
formation and Referral										X						X							2
porary Respite or Relief	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	21
ily Training or Counseling	X	X	X	X		X	X		X	X	X			X	X	X	X	X				X	15
memaker	X						X		X		X		X				X	X					7
ore Services	X						X				X												3
usekeeping	X						X				X												3
om/Board for Family (for traveling related to provision of care)			X								X												2
TOTAL:	13	8	13	12	4	10	14	12	12	7	14	5	5	12	5	4	6	7	7	4	4	10	
ovisions for permitting nique services not vailable elsewhere	X	X	X	X	X		X	X		X							X		X			X	11

adaptive equipment (20 states). The least noted services are information and referral and room and board for family members (two states). Maryland and Nebraska offer the most comprehensive array of services (14 services), while Indiana offers the fewest (three services).

Discussion

It is encouraging that nearly all states have initiated family support programs of some kind. Though conclusive evidence is not presently available, the worth of these programs is not easily denied in terms of their benefits to the child with developmental disabilities and his/her family. Moreover, many states argue that family support programs can result in significant long term cost savings to taxpayers (e.g., Florida and Michigan). But much more still needs to be achieved. Recall that the majority of states lack extensive family support services. Additionally, survey results suggest that even where extensive service systems exist, surprisingly few families are served.

Establishing an effective state-wide family support program, however, is a complicated task requiring consideration of several philosophical and programmatic concerns. The substantial variance among existing programs demonstrated by this survey suggests that little consensus has emerged regarding the most efficient and effective means of administering such programs. Among the several issues that must be resolved are: The role of the family, program eligibility, means of service administration, permissible services, and the potential for consolidating resources across various disability groupings.

The Role of the Family

Though the great majority of persons with developmental disabilities have always remained at home, recent policy in the human services field often discounted the family's role in providing care (Skarnulis, 1976; Demos, 1983). Family incompetence in providing care was frequently presumed while professionally supervised residential arrangements were funded instead.

Survey results suggest that recent calls to "support not supplant" the family have not gone unheeded as numerous states have initiated comprehensive family support programs. Growing numbers of family support advocates, however, have articulated a need for programs where the locus of control over programs rests less with the state and more with the family. In other words, services should be "family driven."

Such programs would empower families on multiple levels by encouraging their active participation in planning the service system and according them some control over selecting the services they receive (Griss, 1984; CSR 1983). The degree of control held by families in existing programs is not clear. One can speculate, however, that cash assistance programs (as opposed to the provision of services) have a greater potential for empowering families because they provide them with increased purchasing power by placing dollars directly into their hands. As a result, instead of being accountable primarily to state funding agencies, service providers are held accountable by individual families. The small number of cash programs suggests that state officials are unwilling to turn over this much power to families and prefer that the locus of control remain with government.

Program Eligibility

States cannot afford to provide comprehensive services to all families who have members with developmental disabilities. Consequently, service planners must devise equitable criteria for restricting the number and/or type of persons served. In structuring such criteria, several hard choices must be made. For instance, all states require that a family member have a "developmental disability." However, should the functional definition of developmental disabilities in the federal law be applied or should eligibility be restricted to conditions such as mental retardation, autism, or multiple impairments? Many states have chosen to restrict the definition, while others have adopted more lenient criteria. Certainly this aspect of eligibility raises the spectre of competition among various disability groups (See Part III; Chapter 1). Likewise, states must decide whether families confronting similar problems should be treated similarly or whether families should be served based on their amount of financial income (Brown, Johnson, & Vernier, 1983).

Who should receive services is a preplexing issue that severely tests a society's capacity for equitably distributing scarce resources to those in need. The existing variance among state eligibility criteria reflects each state's own solution to the problem. Such variance, however, has resulted in an inequitable national response to providing family support since families are treated differently from state to state.

Means of Service Administration

Survey results suggest that services can be made available to families through at least three administrative formats: cash assistance, supportive services or some combination. Each of these formats, however, have certain strengths and weaknesses.

Cash assistance programs. As noted earlier, this approach is favored by many because it shifts the locus of control away from the state and toward parents. With time, the aggregate purchasing preferences of families dictate the types of services that are available and service providers are held accountable directly to parents.

But this approach also raises several issues of note. First, should parents be provided cash prior to purchasing needed services or should they be reimbursed after they have already incurred certain service related expenses? It would seem that receiving cash prior to purchasing services would relieve the strain on family resources. In contrast, the state might prefer a reimbursement strategy because it would be easier to direct and track what is purchased.

Second, should cash received by parents be considered taxable income? If viewed as income, the state could be placed in the undesirable position of subsidizing federal tax revenues. Further, such income could jeopardize a family's eligibility for other public assistance benefits. In contrast, if cash assistance is viewed as a "benefit," the cash received by parents would not be taxable and would not affect eligibility for public assistance.

Finally, cash assistance programs presume that parents have sufficient knowledge regarding the needs of their child or adult with disabilities and the quality of available services. To the extent they do, they will spend their cash efficiently. But some parents may be unprepared to choose and purchase services wisely. Thus, many believe that cash assistance programs must be complemented with case consultant services and parent education to provide parents with the knowledge they need to choose appropriate services.

Supportive services programs. Most states with family support programs elect to provide supportive services primarily. The advantage of this approach is that the locus of control rests with the state and various service providers. As a result, a cohesive service structure can develop throughout the state that can be directed and monitored centrally.

Ironically, this asset is considered by some analysts to be a liability. Though families help decide which services they receive in this scheme, the types of services and the service providers are pre-determined by the state. Consequently, families take a secondary role in deciding which services are needed and which services should be funded. Additionally, because the state contracts with service providers, providers are accountable primarily to the state and secondarily to parents.

Combination programs. These programs offer an opportunity to develop a system that maximizes the relative strengths of cash assistance and supportive administrative styles, while minimizing their weaknesses. There are at least two unique advantages to this approach. The first pertains to funding. Review of existing cash assistance programs shows that the funding source is often state revenue. By adopting a combination approach, however, available resources can be expanded by acquiring federal Title XIX dollars (through the Community-based Waiver Program) to fund certain supportive services like parent education or respite services. Rhode Island is one state that has pursued this course.

Second, if the primary service goal is to promote family independence from the state, combination programs can be very effective. Initially, families may primarily need supportive services (e.g., parent training to learn specialized skills). Later, after their skills and confidence grow, families can take increasing responsibility for directing their own services by giving up inkind supportive services in favor of cash assistance.

Permissible Services

Survey results show that the type of services available vary by state. Some states offer few services while others provide an extensive array. Additionally, state agencies tend to fund service categories (e.g., respite, transportation, parent education). No two families, however, have identical needs. Moreover, existing needs are not static but evolve with time. A preferable program design would include multiple service options that could be tailored to individual families. In this way, instead of being restricted to certain services, families could choose from a menu of permissible services. While some families could benefit from professional advice before choosing services, the primary intent of this type program is to develop services that revolve around and exist for families.

The Potential for Consolidating Resources

Families who have members with developmental disabilities are not the only families in need of support services. Other families that could benefit from such services are those with members who are elderly (Callahan, Diamond, Giele, & Morris, 1980; American Health Planning Association, 1984), adolescent mothers (Klerman, 1983), and chronically mentally disturbed (Hart; 1983; Doll, 1976; Goldman, 1982). Given current economic realities, considerable interest is evolving for consolidating existing human service resources so that programs "crosscut" disability categories. Exemplifying this point, Abels (1984) describes a Wisconsin based family support program that provides a variety of services including case management, consumer training, and cash subsidies to families with members of four disabilty categories (elderly, developmental disabilities, physical disabilities, and mental illness).

Many believe that this type approach is superior to those that result in separate systems for each disability type because it is cost efficient and encourages coalition building among various disability interests. Designing these programs, however, will not be an easy task. Difficulties can be expected with regard to establishing equitable eligibility criteria between groupings and gaining consensus over the type and level of resources that should be expended for each participating group. In addition, even if these problems were overcome, program administrators would be faced with ongoing difficulties related to writing and implementing program standards that cut across disability categories.

PART III: CONTEMPORARY SERVICE DIRECTIONS

Chapter 1: Policy Options for Family Support Services

Chapter 2: Families and Future Financial Planning: National Survey Results

Chapter 3: Using Tax Policy to Support Families

Chapter 4: Using Private Sector Resources to Support Families

Chapter 5: Evaluating Family Support Programs

Chapter 6: Family Support Options: A Policy Perspective

POLICY OPTIONS FOR FAMILY SUPPORT SERVICES*

by

Paul J. Castellani, Ph.D.

Family support services have become the focus of a great deal of attention in the field of services to people with mental retardation and developmental disabilities. A number of new programs in this area are being developed in several states. Other states are reconfiguring service options to more explicitly identify and manage the family support services they have provided. Overall, there is a wide variety and diversity of approaches in these programs across the states. As states seek to broaden existing programs, develop new ones, or to look for indicators of national trends and federal policy affecting family support services, the diversity provides an intriguing array of experiments which may suggest policy choices. Additionally, there have been several legislative and regulatory initiatives at the federal level which may affect the availability of family support sources.

The purposes of this paper are to examine the major dimensions of existing family support service programs and to review the several policy options that are central to the development of such programs. Specifically, discussion will focus on four emerging issues pertaining to the underlying goals and administration of family support programs including: 1) What are family support programs? 2) Who should these programs serve? 3) How should these services be delivered? and 4) How should these services be funded? When examining each of these questions, information will be provided regarding policy issues, current responses, and potential policy options. In all cases, such discussion will explore the political feasibility and desirability of some of the major family support directions.

---

* The positions expressed in this paper are solely those of the author and do not represent those of the New York State Office of Mental Retardation and Developmental Disabilities.

What Are Family Support Services?

Policy Issues

The definition and identification of family support services involves several important policy problems. Even a brief review of the literature in this area and the experience of the several states that have explicitly identified family support service programs indicates the extremely wide boundaries of this area. Moreover, the recent history of support services and their emergent and embryonic character further complicate the problem of definition.

Generally, family support services can be defined as those services, in addition to core residential services, that developmentally disabled people require for normal community life. There is, however, virtually no attention in the literature to the definition of the specific services encompassed under the rubric of family support services. Moreover, an examination of the availability and accessibility of family support services in New York State showed that they were often subsumed in other services and were only identified and defined as family support services because of arbitrary analytic frameworks (OMRDD, 1983).

The history of the development of family support services explains some of the definitional ambiguity. The need for support services first became apparent when they became linked to deinstitutionalization and success in community living (Gollay, et al., 1978; Intagliata, et al., 1980; Braddock, 1981; Bachrach, 1981). Persons leaving institutions have been the primary focus for the development of these services, although the overwhelming majority of people with developmental disabilities live at home with their families and often need the same type of services. To a large degree, support services to this latter group have been developed subsequent to and with less resources than those for the former group. Thus, the services that have become widely known as "family" support services were initially and largely developed as "placement" support services. An understanding of the evolution of such services, therefore, is important in order to clarify who the intended recipients of family support services should be, and how the objectives for such services should be characterized.

Current State Family Support Services

The conceptual and historical ambiguities are also compounded when we examine the experience of states with family support service programs. Figure 1 shows the array of family support services in 17 states gathered from a survey of these programs by the New York State Office of Mental Retardation and

Figure 1: Services Offered in 17
Family Support Programs

SERVICES	STATES																
	ND	FL	ID	CT	MI	IL	PA	MN	NB	CA	MD	WA	MT	OH	NV	SC	RI
TRANSPORTATION	•	•	•	•	•	•	•	•	•	•		•	•		•	•	
RESPITE CARE	•	•	•	•	•	•	•	•	•			•	•	•	•		
ADAPTIVE EQUIPMENT	•	•	•	•	•	•		•		•		•	•	•	•	•	
EDUCATION & TRAINING	•	•		•	•	•	•	•	•	•			•	•			•
SITTER/COMPANION	•	•	•		•		•	•		•	•			•	•	•	
FAMILY COUNSELING	•	•	•	•	•	•		•	•				•	•			
MEDICAL/DENTAL	•	•	•	•	•	•		•	•		•					•	
HOME BARRIER REMOVAL	•	•	•		•	•		•	•	•				•		•	
SPECIAL CLOTHING	•	•	•	•	•	•		•							•	•	
SPECIAL DIET	•	•	•		•			•			•			•	•		
INDIVIDUAL COUNSELING	•	•	•	•		•			•				•				
MEDICATION		•		•	•	•		•	•		•						
DIAGNOSIS & ASSESS.	•	•	•		•	•		•	•								
PHYSICAL THERAPY*	•	•	•	•	•		•					•					
OCCUPATIONAL THERAPY*	•	•	•	•	•		•					•					
SPEECH/HEARING THERAPY*	•	•	•	•	•		•					•					
HOMEMAKER						•	•	•	•	•	•						
HOME HEALTH CARE	•		•		•	•			•		•						
BEHAVIOR MANAGEMENT*	•	•	•	•			•					•					
PERSONAL CARE					•	•			•	•	•						
CHORE						•			•	•	•						
DAY CARE		•	•	•		•											
VISUAL/MOBILITY TRNG.*	•	•		•			•										
VOCATIONAL THERAPY*	•	•		•			•										
RECREATIONAL THERAPY*	•	•		•			•										
RECREATION/LEISURE	•		•				•										
HOUSEKEEPING										•	•						
BASIC CARE SUBSIDY	•																•
INFORMATION & REFERRAL													•				
OTHER/INNOVATIVE	•	•	•	•	•		•	•		•	•	•	•		•	•	
# OF SERVICES OFFERED	23	22	19	18	18	16	14	14	13	10	10	8	8	7	7	7	2

*DELIVERED AS AN IN-HOME SERVICE

Source: Bird, W. A. A Survey of Family Support Programs in Seventeen States (Albany, NY, New York State OMRDDm 1984)

Developmental Disabilities (Bird, 1984).* There have been other recent reviews of state family support services (e.g., NASMRPD, 1979; Bates, 1983 and the survey results presented in Part II, Chapter 3). Before commenting on Figure 1 it is important to note two things about these surveys. First, while every effort is made to ensure the accuracy of the information, many states operate more than one family support service program and/or subsume them under other programs. Therefore, there are occasional discrepancies between surveys. Second, family support services are developing and changing so rapidly that surveys of this sort tend to become out-dated rather quickly. Nonetheless, these recent surveys do provide an important insight into what various states have defined as family support services. As shown in Figure 1, virtually the entire range of therapeutic services are being offered as family support services.

Policy Options and Implications.

The historical and conceptual ambiguity surrounding the development of family support services is reflected in the considerable variation in what states see as family support services. Thus, the question of what options should be pursued is ultimately dependent on what is politically and fiscally prudent within a particular state context.

*** In this paper Dr. Castellani uses information gathered from a survey of 17 states with family support services conducted by William Bird of the New York State Office of Mental Retardation and Developmental Disabilities. Though the survey of family support programs described earlier (Part II; Chapter 3) presents information of a similar nature, the reader may note that the results of these two surveys differ somewhat.**

The widespread attention given to family support services by professionals and advocates, the increased number of states instituting programs in the area, and the increases in the number of services provided under the framework by states with family support services programs suggests that an inclusive definition is preferable. This may be very attractive in the short-term. In the long run, this approach risks the dissipation of political support because it attempts to do too much. This could occur because of the inability to define clearly what is needed or because the costs of an apparently open-ended list of services will soon frighten legislators and others who will be called upon to fund these programs.

The most prudent long-range approach to ensure and enhance the availability of family support services is to begin by recasting the definition for these services in a simpler and more politically manageable framework. Simply put, families should be the focus of family support services. As pointed out earlier, many states developed family support services by expanding services that had been made available to individuals placed in the community to people living at home with their families. Thus, the family became the ultimate community-based facility. This approach obviously ignores the highly individual character of families providing care to developmentally disabled sons and daughters.

Though tailoring services to meet the needs of families is increasingly part of the rhetoric in the field, the reality of service delivery falls short of the ideal. A review of the goals of family support services may be helpful in closing the gap.

The major goals are: 1) to strengthen the family structure in order to enhance the quality of care families provide to a developmentally disabled member, and 2) to prevent undue out-of-home placement? To what extent do family support services strengthen family structure, and secondarily, prevent placement. Addressing the question in this way should help to determine what services should be encompassed in family support service programs and who the recipients should be.

If we return to the starting point of what families need, the range of services that would be encompassed within the framework of family support services narrows. Many of the services listed in Figure 1 are core habilitative services provided for the person with a developmental disability in the home setting. These are typically provided by someone who comes into the home. While these services may be clinically necessary or more convenient for families, they do not directly strengthen the family structure. Indeed, a careful review of the services in Figure 1 from the perspective of strengthening the family structure, or enhancing the family's capacity to provide care, would result in a narrowing of the range of family support services.

With the exclusion of Basic Care Subsidy, which is not actually a service in this context, and with some collapsing of categories such as family counseling and individual counseling into counseling, the following is a list of family support services that directly strengthen or enhance a family's capacity to provide care:

- respite
- counseling
- homemaker
- recreation
- transportation
- special diet and clothing
- home barrier removal
- diagnosis and assessment
- information and referral

Indeed, the last three, home barrier removal, diganosis and assessment, and information and referral, are typically one time services. Thus, the list of family support services that might be provided on an on-going or occasional basis narrows further.

In summary, the answer to the question "What are family support services?" is complex and problematic. However, enhancing the availability and stability of these services requires an approach that narrows the range of family support services to those that directly support and strengthen the family. The expectation is that this focused approach will be both functionally and politically attractive.

Who Should Receive Family Support Services?

Policy Issues

The question of who the recipients of family support services should be is a central issue in this area, and, like the others, it is complicated. It includes both a strategic question of the approrpriate overall focus of family support services as well as the more practical, but nettlesome issues, of how are specific eligibility determinations to be made.

First, we should address the strategic issues. To a large degree, these issues are also linked to the basic goals expressed for family support services noted above -- to strengthen families and to prevent institutionalization. A close examination of these goals with respect to eligibility for family support services reveals a major problem. That is, if we choose to strengthen families, this would seem to argue for a very broad definition of who should be the service recipients. Indeed, Moroney (1981) proposes the universal provision of support services to families caring for a developmentally disabled family member at home. The most obvious problem with this approach is the political infeasibility of an entitlement strategy at a time when existing social welfare entitlements are being reconsidered.

Another problem with a universal approach towards eligibility is the lack of certainty regarding the magnitude of need among certain segements of the developmentally disabled population. Estimates for autism, neurological impairment, and learning disability for instance, are problematic. Advocates for these groups of disabled people have often argued that their numbers are substantially larger than estimates used by government agencies. Moreover, they have been especially vociferous in demanding services for unserved and underserved persons who typically live at home or in other independent community settings. This is especially important since advocates for these disability groups view family support services as a vehicle for access into the developmental services system and a mechanism for expansion of services overall (Castellani & Puccio, 1984).

Further, a more inclusive elgibility standard may generate tension among disability groups. It has been shown that access to family support services is highly dependent on enrollment in regular and routine day programs, and these are more typically used by people with mental retardation (OMRDD, 1983). Publicly, advocates and providers of services for mentally retarded persons have been supportive of family support services for a range of disability groups. Informally, however, they have been more cautious since they are aware that, in an era of continuing resource scarcity, additional services that encompass other disability groups may result in less for those currently being served. Thus, a general entitlement approach may create competition between those currently enrolled in programs (and thereby receiving family support services as well) and those other groups of developmentally disabled persons who have been outside the service system and who desire new services (such as family support services).

Another problem with a universal approach to eligibility concerns the potential shifting of clients from generic to specialized services. Many people with developmental disabilities, particularly those with autism, learning disabilities, cerebral palsy and other neurological impairments are currently receiving services from social service, health, mental health, and rehabilitation service providers. The expansion of family support services to those living at home, particularly those people with low incidence disorders, creates the possibility that clients and families currently served by other systems may move into the developmental disabilities service system. Though, this may be appropriate, providing services to those served by other generic agencies may dissipate resources available for the unserved and underserved.

Clearly, providing a modicum of services to all families to strengthen their capacity to care for a developmentally disabled member can be very costly. At the core is the question of whether: 1) few services are to be provided to virtually all families, 2) whether more services are to be provided to all families, or 3) whether more services are to be provided to those most in need. The problems inherent in the more universal approach have been described. The alternative, focusing on those in need, also involves problems.

The first question concerns what constitutes need. The second goal of family support services, preventing unnecessary out-of-home placements, represents one way of determining need. However, that criterion obviously does not represent either the most extreme or exclusive measures of need for family support services. The overwhelming majority of families caring for a disabled member at home are not likely to request an out-of-home placement, but many may need family support services. However, when we consider needs in a more individually oriented context, a variety of problems arise.

The criteria for services have, to this point, been almost exclusively based on the disabled person's needs. A wide variety of assessment tools is available to ascertain a person's functional and service requirements. To determine the level of need of a family is more complicated. Designing services that enhance a family's capacity to provide care at home and/or that prevent out-of-home placement requires a knowledge of specific familial and situational characteristics that may bear on these outcomes.

Several of these characteristics are suggested in the growing body of literature in this area (Tausig, 1984; 1985). In addition to the level of disability experienced by the disabled person, these characteristics fall into three main categories: age, family structure, and limitations on access to services. Age encompasses a variety of situations. It is becoming apparent that families experience crises that affect their ability to cope with a developmentally disabled member at several life stages. These include: the period around the birth of a developmentally disabled child, when the family is confronted with the problems of identifying needs and getting early intervention services; the point at which a disabled child enters school; the emergence of the child into adolescence; and when a child "ages out" of school programs; and when the age of the parent(s) of a developmentally disabled person brings diminished physical or economic capacity to care for that individual at home.

Family structure issues include problems faced by single parent families, excessive stress caused by the presence of a disabled member, and the number and characteristics of other siblings or family members either requiring care or able to provide care. Access issues affect persons not currently enrolled in MRDD programs, and ethnic, racial, and language minorities who tend to be unserved and underserved by current programs. This also includes persons with low incidence developmental disabilities who are similarly unserved and underserved, and families with low incomes or who are geographically and socially isolated from MRDD services.

Although these family and situational characteristics have been suggested as factors that affect a family's ability to care for a developmentally disabled member at home, it is extremely difficult to measure their impact and use them to establish service priorities.

Eligibility Criteria in Current State Programs

Figure 2 shows the eligibility criteria currently employed in state family support services programs. It is apparent that many of the factors that have been suggested as important in creating needs or, conversely, strengthening families and preventing out-of-home placements, have not been explicitly included. Eight of the 17 states surveyed require that risk of out-home-placement be established, which can of course encompass other factors. Income level, used by nine of the 17 states as a criterion, can also be a surrogate measure of some of the other factors indicated in the literature. The other two eligibility criteria, age and level of disability, are obviously specific to the individual with the developmental disability. There seems to be no direct inclusion of criteria that are linked to such specific needs of other family members such as number of siblings, others in the family in need for care, capacities of parents or other family members to give care, or housing configuration.

Policy Options for Eligiblity Criteria

It is clear that as states develop and expand family support services, they must deal more explicitly with the strategic and

Figure 2: Program Eligibility Criteria in 17 Family Support Programs

STATES	AGE	AT-RISK OF INSTITUTIONAL PLACEMENT	LEVEL OF DISABILITY	INCOME LEVEL
CA				SSI eligible
CT	under 21	required		middle income families ineligible for public assistance
FL		required		
ID	under 21	priority		
IL		required		sliding scale based on gross income and family size
MD	over 65	required		SSI eligible
MA	under 18	required	severely or multiply disabled	families ineligible for SSI or public assistance due to income
MI	under 21		severely or multiply disabled	
MT			severely disabled	
NB			severely or multiply disabled	family income insufficient for cost of care
NV			profound mental retardation	gross income, family size, cost of care
ND	under 21			families ineligible for other programs
OH			substantially disabled	sliding scale based on taxable income
PA				
RI				
SC		required		family resources inadequate to cover special needs
WA		required		

Source: Bird, W. A. A Survey of Family Support Programs in Seventeen States (Albany, NY, New York State OMRDD, 1984) practical issues involved in the central problem of who is to receive family support services. Continuing experience with these programs should provide an enhanced capacity to measure needs more accurately and link appropriate services to those needs. That will depend, in part, on undertaking well-designed evaluations of those efforts. Nonetheless, practical problems as well as the strategic issues (e.g., who is to be served by family support services) are likely to be resolved politically rather than through some process of rational planning and evaluation. There simply are no objective measures of need on which to base service determinations for individuals or groups when the standard is to enhance a family's capacity to provide quality care. Capacity is both relative to others' situations and to society's changing expectations of what constitutes an acceptable or desirable standard of living. Given the political character of such determinations, it seems unlikely in light of fundamental reconsiderations of entitlement programs at federal and state levels, that a broad and inclusive approach to eligibility will be a policy option that will emerge.

How Should We Deliver Family Support Services?

Policy Issues and Current Options

The question of how family support services are to be delivered raises several important policy issues. These include:

- the level of government best suited to manage these services;
- the extent to which family support services conform to or compensate for community conditions;
- the relationship of public and private sectors (voluntary and proprietary) in delivering family support services;

- the degree to which these services are to be provided by generic or specialized agencies;
- the degree to which families are empowered to exercise choice in the type, amount, sources, and use of family support services.

The issue of which level of government is best suited to manage family services throws into relief the question of whether a large bureaucratically oriented system can oversee a more personalized and individual program of family support services. In some ways, even community residences and intermediate care facilities for mentally retarded persons are imposed on communities, and federal and state regulatory structures tend to ensure uniformity in those service models. Family support services, however, are more intimately linked to the communities in which they operate than other residential and day programs. The diversity of communities suggests that management structure must be flexible. The relatively uniform management models that were designed to operate similar institutions across a state cannot be expected to function well in various community settings. As illustrated in Figure 2, slightly more than one-half of the programs examined in a recent survey are administered at the local level. However, the question of the level of government best suited to manage family support services must be considered with regard to several other factors that will be discussed below.

The extent to which family support services are intended to conform to or compensate for community conditions is one of the most crucial factors affecting the management of programs in this area. At stake here is a basic question of equity within and among locales. In the first instance, much more needs to be known about the environment in which we expect family support services programs to operate. We are aware that family support services are related to such community resources as the availability and accessibility of public transportation, recreational facilities, medical, dental, and other professional services. It is also apparent that these services and resources vary widely by locale. In one respect, local management of family support services can best take into account local needs and resources. On the other hand, the intimate link between family support services and often widely varying community resources raises the question of whether family support services should equalize the differences in availability and accessibility that are likely to result. Clearly, institutional models, especially those supported in part through Medicaid funding, are operated on the principles of "statewideness" and equal access. Placement support services, as pointed out earlier, were in many instances initially built around community residences for deinstitutionalized persons and served as models for family support services for individuals who had never resided in an institution. This creates a strong precedent for equalizing the availability and accessibility of family support services across local governments to compensate for comparative deficits in resources and services.

The relationship between the public and private sectors, including voluntary and proprietary, is another concern that must be addressed in the delivery of family support services. Many states have a variety of state government, local government, and private agencies involved in the management and delivery of community-based services. The pre-eminence of one or another sector in various locales is a function of historical, political, economic and other factors that may confound rational program design, but are nonetheless powerful in shaping future programs. Management and delivery of family support services may result in differential outcomes depending upon the auspices of provider.

Private proprietary management (and ownership) of acute and long-term care health facilities has provided examples of economies of scale and models of efficiency that may merit consideration for the management of at least some family support services for developmentally disabled people (Zuckerman, 1983). An obvious concern, however, is accessibility to services by clients and families who may present complex, unusual, troublesome, and other problems that make them commercially unattractive. A lack of willingness to serve these clients may also be expected on the part of private voluntary agencies. Moreover, many private voluntary agencies have traditional disability orientations, religious, ethnic, racial and geographic identifications or affiliations that serve to limit accessibility to many families in need of support services.

State government has been the provider of last resort and might be expected to be the focus of a management structure ensuring the greatest degree of availability and accessibility

(OMRDD, 1983). However, state government-operated services tend to be the most expensive and may be limited by an institutional bias and historical perspective that may inhibit delivery of family support services to unserved and underserved populations (Commission on Quality of Care, 1984). In addition, difficulties with maintaining an acceptable level of operating flexibility in a large bureaucratic structure must also be considered. The use of public non-profit agencies established for the purpose of managing the delivery of family support services is another structural option. Here a key issue is the degree of authority that type of agency might exercise vis-a-vis other governmental agencies in coordinating and gaining access to services for its clientele.

No one model need be selected to the exclusion of others across an entire state, nor is this discussion intended to suggest that services cannot function conjointly or collaboratively. It is intended to indicate that family support services represent a substantially distinct type of service, and we should not assume that management models derived from institutional perspectives or even community residential and day program services are appropriately or easily adapted for family support services.

Another major issue of service delivery and management is the extent to which we create specialized family support services or integrate these services into social welfare, education, health, mental health, and other service domains. We are all familiar with the problems associated with gaining access to generic or "semi-generic" (Boggs, 1981) services. However, the limitation on resources available for the development of family support services raises the question of whether we can prudently advocate for a separate and parallel system of services, or more importantly, whether legislators and other policymakers will be responsive to such an argument. As indicated earlier, many of those who would be eligible for family support services are already being served by other service systems. Moreover, some of the specific family support services such as transportation and homemaker services are not specific to developmental disabilities. In any case, the management of family support services programs requires a greater degree of coordination among providers and consumers than other community-based services. The broad clientele in widely dispersed settings as well as the intermittent nature of delivery requires that systematic coordination be built into the management of services. Case management is frequently proposed as a mechanism to solve the problems of services coordination (Intagliata, 1982; Schwartz, Goldman and Chrugin, 1982; Boggs, 1981). However, the cost and effectiveness of case management have also been questioned (LCER, 1983; Beatrice, 1980) and we should be sensitive to the trade-offs between actual services delivered and coordination.

The degree to which families are empowered to exercise choice in the amount, type amount, source and use of family support service is another important policy issue affecting the delivery of family support services. Indeed it appears to be emerging as one of the most central and politically sensitive issues in this area. While there are many aspects of this issue, the basic question concerns the structure of services and the mechanisms families can use to gain access to those services.

As was pointed out earlier, many states began support services programs when it became apparent that people who had been placed out of institutions were returning or having problems because the so-called generic services that were expected to be available were not. It has often been only secondarily that states provided support services to families as spin-offs of placement support services or in belated recognition of the needs of families caring for a developmentally disabled member at home. Thus, the progression has been to first ensure that those services that had been available in institutions were provided to individuals placed in the community and then attempt to make those services available to people living at home with their families. In many instances, these family support services are provided as direct service adjuncts to core residential and day programs (OMRDD, 1983).

The increasing demand for and use of family support services has raised several problems and concerns with the direct provision of services model. As experience grows, it is becoming increasingly apparent that families are radically different than institutions, even those that are community-based. The structure of service delivery is primarily institutional, and the problems and opportunities families present seem to confound or be confounded by that structure.

The family is often the setting where family support services are provided. In many instances, the family is the provider of services. The family is also the consumer of services, and these roles often occur at the same time. Government regulations, policies, guidelines, and funding formulas do not typically or easily deal with the somewhat simultaneous overlap of roles that occur in providing family support services.

One response to these problems has been to increase the number of service options in family support programs. There is a very wide array available in many states (see Figure 1), and the tendency has been to increase the number of services offered. However, this still results in a product-driven system. That is, families' choices are limited to the services made available by the state or agencies contracted to provide family support services.

Another response to these concerns is manifested in the increasing number of family support programs that employ cash subsidies and/or vouchers. Figure 3 shows that 14 of the 17 states included in a survey of family support programs use a subsidy and/or voucher mechanism, although they tend to be relatively limited in scope. Cash subsidies and vouchers although limited in amount and occasionally to specific types of services, represent a substantial alternative to direct provision of services. This results in increasing the discretion of the family. Further, the simplicity of cash subsidy approaches may be more attractive to governments in light of the complexity of dealing with the family as provider and consumer.

Summary

The answer to the question of how we should deliver family support services is obviously complex, as the discussion of the several issues encompassed in that question suggests. These issues, perhaps more than any of the others involved in the entire area of family support services, are highly conditioned by each state's experience in delivering services to people with developmental disabilities and the political-economic environment in each state. New York State, for example, has a large state-operated system of services complemented by services provided by large voluntary agencies. Local governments play a very limited role in the direct provision of developmental services, and there has been virtually no experience with vouchers or cash subsidies and little apparent movement in that direction. Pennsylvania has had a very large family support services programs for a number of years which operates largely through provision of services through county government. Other states are likewise conditioned by their history in this area.

Nevertheless, there are factors that seem either inherent in the nature of family support services or at work in the political-economic environment that will shape the direction of delivery of these services. Family support services are closely linked to the communities in which the needs arise, and it would appear that local governments will have to play an important role in managing and/or delivering family support services. The continuing pressure to contain government spending on social programs seems likely to create more pressure to increase the role of the private sector vis-a-vis the public sector in the area of family support services. Those cost pressures as well as the generic character of many family support services will also encourage greater integration of service delivery and less separate and parallel services specific to people with developmental disabilities. The generally increasing role of propriety providers in virtually all areas of human service delivery will undoubtedly be seen in family support services as well. These entrepreneurial opportunities are certain to increase to the degree that cash subsidies and consumer control increase. As suggested earlier, the demand for cash subsidies, vouchers and other mechanisms that tend to empower families seems to be emerging as a companion to the demand for these services in general. None of these observations should be especially surprising. However, taken together, they indicate that family support services represent an increasingly significant departure in the way in which services are provided to people with developmental disabilities and their families, and they may ultimately have a reciprocating effect on the entire system of services for disabled people.

Funding Family Support Services

Policy Issues

The financing of services is obviously a central concern. This question has been closely linked to two recent issues that engendered substantial discussion and controversy. These are the Home and Community Care Waiver provisions (Sec. 2176; PL 97-35), and the Community and Family Living Amendments of 1985 (S. 873)

-- the so called Chaffe Bill. An appreciation of these issues will be enhanced by examining them from the following basic perspectives:

- What are the current sources of funding for family support services in the future?
- What will be the sources of funding for additional family support services?

Current Sources

Much of the discussion about family support services concerns strategies for increasing funding. To some extent it ignores the current bases of funding that are usually the best predictors of the future (Wildavsky, 1964). Moreover, this discussion also ignores some problems which threaten the current bases of funding family support services.

The answer to the first question about funding sources is that state tax level dollars constitute the largest source of funding for family support services (Braddock, 1984). Despite the importance of the issues raised in the debates on S. 873 and the Home and Community Care Waiver, arguments for increasing the amounts of funding for these services should take into account the fiscal commitment made in each of the states to these services. Figure 3 indicates that for those states surveyed by Bird (1984), the levels of funding varied widely and also represented a relatively small proportion of the states' total spending for developmental services. Another important aspect of the issue that was pointed out by a study of family support services in New York State was that funds for these services were often not specifically identified or budgeted (OMRDD, 1983).

That is, family support services were provided as adjuncts to routine day and residential programs. It should be pointed out that many ICF/MRs, community residences and day treatment programs, are supported in part with federal funds. Thus, at least some federal funds are used indirectly in family support services. Nonetheless, as rate setting methodologies established tighter controls on the use of funds or as funding was constrained, family support services which lacked an explicit fiscal rationale became increasingly vulnerable to cut-backs (Castellani and Puccio, 1984). It is very likely that the large number of states without explicit family support services programs may indeed fund the services in similar ways and they may be similarly vulnerable. Overall, the information that we do have on the funding of family support services indicates that states themselves provide the bulk of funds for their support, there are some federal funds used at least indirectly, and that these programs are small and/or not explicitly identified in funding bases.

Sources for Additional Funds

As suggested above there has been an extraordinary amount of discussion and debate about proposals that affect the sources of funding for additional family support services. Federal funds are seen by many as a primary source of potential support for these services. Since the mid 1960's when the federal government expended almost no funds on state developmental services, the fiscal participation of the federal government in this area has increased enormously (Gettings, 1980). Moreover, an overwhelming

Figure 3: Program Characteristics of 17 Family Support Programs

STATES	REPORTED NUMBER SERVED	BUDGET	MAXIMUM ANNUAL COST/CLIENT	METHOD OF DELIVERY	LOCUS OF MANAGEMENT/ CONTROL	PROGRAM SCOPE
CA	102,400	$288,639,000	$2,900*	Individual providers	County	Statewide
CT	10+	20,000	2,000	Cash subsidy	State	Pilot
FL	216	500,000	2,300*	Reimbursement	Region	Statewide
ID	130	45,000	3,000	Cash subsidy	Region	Statewide
IL	n/a	n/a	4,200	Cash subsidy	State	Pilot
MD	60	120,000	2,000	Cash subsidy	State	Pilot
MI	2,140	5,700,000	2,600	Cash subsidy	County	Statewide
MN	187	525,000	2,800	Cash subsidy	State	Statewide
MT	600	1,125,000	1,880*	Services & subsidy	Region	Statewide
NB	90	500,000	3,600	Cash subsidy	State	Proposed pilot
NV	57	110,000	3,400	Cash subsidy	State	Statewide
ND	124	200,000	2,600	Cash subsidy	State	Statewide
OH	n/a	2,000,000	2,500	Services & reimbursement	County	Statewide
PA	15,630	4,887,000	2,000*	Direct services	County/Region	Statewide
RI	66	256,000	2,600 - 3,900	Cash subsidy	State	Statewide
SC	16	22,063	1,800	Reimbursement	State	Statewide
WA	1,900	1,052,000	554*	Direct services	Region	Statewide

*average cost/client

Source: Bird, W. A. A Survey of Family Support Programs in Seventeen States (Albany, NY, New York State OMRDD, 1984) proportion of federal funds is devoted to intermediate care facilities for the mentally retarded (ICF/MRs) and the majority of those funds to larger facilities of over 15 beds (Braddock, 1984). Clearly, the enormous role of federal funds in this area has also focused attention on sources of additional funds for family support services. Two proposals have been at the center of the discussion. Specifically, the Home and Community Care Waiver and the Community and Family Living Amendments of 1983.

The Home and Community Care Waiver would allow a state to finance a community-based system of care by eliminating ICF/MR beds and reinvesting those funds in home and community-based services. The waiver has obviously been suggested as a vehicle to increase the availability of family support services. However, it is widely recognized that the waiver is intended to be a mechanism for cost containment (Fernald, 1984). The waiver formula requires that the number of Medicaid beneficiaries after the waiver be less than or equal to the number of beneficaries before the waiver. Thus, there is a fiscal disincentive for states to use the waiver to expand and extend services to new recipients, particularly the large number of families caring for a disabled member at home and currently not receiving any services. Despite some initial enthusiasm about the prospects for expanding family support services through the Home and Community Care Waiver mechanism, this does not seem to be a currently attractive possibility.

The Community and Family Living Amendments of 1985 (Senate 873), introduced by Senator Chafee, are intended to bring about a radical change in the states' fiscal incentives to use Medicaid funds for community vis-a-vis institutional services. In summary, the intent of the so-called Chafee Bill would be to remove and/or create substantial fiscal penalties over time in the federal financial support for residential facilities serving over 15 persons. Since the initial introduction of the legislation there have been a variety of modifications and counter proposals that would generally soften the immediate impact on states with substantial institutional populations. Nonetheless, the intent of the proposal remains substantially the same. Supporters of the proposal argue that the impact of the passage of this legislation would be to force the phase-out of large institutions and conversely provide a large financial incentive for states to develop community and family support services programs. Opponents of the proposal have argued that size alone is not an adequate measure of quality of care and that the provisions for implementation create a differential and inequitable impact on states. Most opponents of the specific proposal, S. 873, do tend to acknowledge the desirability of a community-based rather than institutional system of care.

Major public policy changes such as those involved in the Community and Family Living Amendments typically take place over a period of time; often several years. Nonetheless, there seems to be considerable energy within the developmental disabilities field for changes in the general direction of the Chafee Bill. Moreover, there is substantial pressure being exerted by the federal government to contain Medicaid costs, and proposals such as S. 873 could complement those efforts in some important respects. Community and family support services are perceived to be less costly than institution based services. Thus, there is a good possiblity that a variation of S. 873 will ultimately be enacted, resulting in an increase of federally-funded community-based and family support services.

States, as pointed out earlier, are currently the primary source of funding for family support services (Braddock, 1984). Thus, it would also seem likely that they be a major source of a additional funds. Indeed, the expansion of state-funded family support services programs indicates that these programs are one important area of new program development in the states. The relatively small amounts of funds available in these explicit programs (Figure 3) are somewhat misleading since many programs are very new, and, as noted above, it is likely that many states fund family support services without an explicit fiscal identification of those services (OMRDD, 1983). The attention devoted to family support services suggests that programs in this area are likely to increase in number and size. An additional factor that may affect the states' ability to fund programs in this area is the budget surplus recently accumulated in several states as a result of federal tax changes and an expanding economy. The extent to which these new funds provide a target for advocates for these family support services will also depend, in part, on those states' efforts to cut taxes rather than fund new or expanded services.

The role of local government in this area is uncertain. On the one hand, it is generally assumed that governments at this level which depend in large measure on property and sales taxes for revenues have neither the capacity or willingness to themselves fund family support services programs. However, some core family support services such as transportation and recreation are typically services provided by local governments. Voluntary agencies which provide substantial amounts of these services such as respite, counseling, and information and referral also rely in part on funding from local government sources. Moreover, school districts either as independent local entities or as components of municipal governments are being pressed to provide more family support services as adjuncts to special education services mandated by PL 94-142. Thus, the role of local government in funding family support services has not been particularly prominent in discussion on this topic, but it seems that closer attention must be paid to the problems and opportunities of financing at this level of government.

Some attention has been paid to private sources of funding for family support services (See Part III; Chapter 4 on use of private sector resources). Most of that effort has focused on the possibilities for inclusion of family support services in either privately purchased or employer provided health insurance programs. The potentially large and usually long-term costs associated with services (including family support services) for persons with developmental disabilities tend to either confound basic insurance principles or prove to be prohibitively expensive

(Kane and Kane, 1978). Proposals for publicly financed national childhood disability insurance (Gliedman and Roth, 1980) have not generated as much interest as direct government provided or funded services programs. Generally, the focus of attention for funding family support services has been on public rather than private sources.

Summary

Discussions concerning the funding of services are typically complex. The specific issues and various mechanisms are indeed very often difficult for lay people and professionals to understand. These discussions do, however, often obscure the fundamental and relatively straightforward issues at stake -- whether to fund an expansion for family support services and who will pay for these services.

Clearly, families caring for a developmentally disabled member at home have borne virtually the entire burden of cost as well as care. The advocacy for increased public, as well as private insurance funding for these services is a political demand for socialization of the costs and risks (Lowi, 1979). The first priority in this process is typically to generate the political energy necessary to place the issue on the policy agenda. This seems to have been achieved to a considerable degree at the federal and state level. Next steps include the identification of funding opportunities. State funds themselves have been an initial and major source of funds for the development of family support services programs, and the energy and diversity associated with those programs is likely to result in an increase in their number and size.

The opportunity for the use of Medicaid funds for community and family support services has become an overriding issue in the developmental disabilities field. While advocacy for overall expansion of these programs continues, it seems that the major political energy is devoted to efforts to reallocate the institutional and community services shares of the Medicaid "pie." In light of the possibility that Medicaid funding will contract, the energy devoted to reallocating what is now available for developmental services may dissipate the political momentum needed to increase funds available for all services, including family support services.

One final overarching concern in the area of funding family support services is the extent to which these services are items on the agenda for long term care reform. Gettings (1980) and others have pointed to the need to broaden the base of funding services (including family supports) beyond a health base. Boggs (1981) points towards that direction in observing:

> ...a newly emerging constituency for long-term care, as earlier defined, appears to be making headway toward legislative reform, what is sought is an alternative funding stream for non-institutional support services in which it will not be necessary to differentiate between homemakers or personal care givers by whether they earn health dollars or social service dollars. (p. 76)

It is apparent that most of the core family support services identified earlier, such as transportation, recreation, counseling, homemaker services and information and referral are not especially disability-specific. It is likely, therefore, that funding for family support services may indeed be an important part of reform of long-term care.

Conclusion

Occasionally there seems to be a tendency in a field dominated by clinical practice to assume that policy choices are similarly subject to somewhat objective professional standards. Indeed, many of the issues discussed in this paper are complex and difficult in their definition and implementation and do require expert attention. However, the identification and discussion of these issues should be attentive to the fact that their resolution is the outcome of a political process. The approach used in this paper was not intended to mirror that in Laswell's seminal work, Politics, Who Gets What, When, How (1936). Nonetheless, the answers to the questions: What are family support services? Who will receive them? How will they be delivered? and how will they be funded?, are fundamentally political.

In many respects, the most crucial stage in the policy process has been successfully negotiated by advocates for increased availability and accessibility of family support services. That is, family support services have been clearly placed on the policy agenda. Moreover, advocates have succeeded in defining their demands in terms of the archetypal good, the family.

The degree to which broad or narrow ranges of family support services are identified will depend largely on the tactical opportunities available to advocates. The determination of who will be served is potentially one of the most divisive within the developmental disabilities community as cleavages surface and become resolved among advocates for previously and never institutionalized persons, individuals with various developmental disabilities, and groups that have been traditionally unserved and underserved by formal developmental services. The issue of how family support services are to be delivered may result in basic restructuring of the provision and use of social services and relationships between government and its clientele as families seek greater empowerment. Finally, the question of how family support services are to be funded will likely be part of a major reform of federal, state, and local fiscal responsibilities for long term care.

The discussions surrounding the Home and Community Care Waiver and the Community and Family Living Amendments have pushed some of these concerns to the forefront. However, very few of the issues discussed in this paper have been explicitly dealt with in the federal, state, and local policy process. We can be sure that the political energy that put family support services on these various policy agendas is sufficient to ensure that these policy choices will be made in the relatively near future.

FAMILIES AND FUTURE FINANCIAL PLANNING: NATIONAL SURVEY RESULTS

by

John Agosta, Ph.D., Beryl Feinberg and Valerie Bradley

Every parent wonders, at some point in his child's life, "What will happen to my child if I die or am permanently incapacitated?" In most instances the response depends on the child's age and family situation. Parents normally expect that as a child approaches adulthood, s/he will be competent to manage his/her personal and financial affairs. For parents that have sons or daughters with developmental disabilities, however, responsibilities do not necessarily diminish with the passage of time. Unique issues must be faced to protect and maintain the health, welfare and financial well-being of persons with developmental disabilities for the duration of their lives.

Several traditional means exist for coping with this problem. Families can:

- Create and contribute to savings accounts and investments in the name of their son or daughter with disabilities under the Model Uniform Gift to Minors Act;
- List their child with disabilities as a primary or contingent beneficiary under a life insurance or pension plan;
- Establish an Individual Retirement Account (IRA) account in the name of the person with disabilities; or
- Establish a will whereby the person with disabilities inherits specified assets.

These alternatives, however, are flawed because they each set conditions whereby assets flow directly to the person with disabilities. This event is undesirable for at least three reasons. First, the person with disabilities may be incapable of managing his or her fiscal affairs and will need assistance. There is no guarantee, however, that the person who provides assistance, however well intentioned, will be willing to or capable of assuming such responsibilities for the long term. Second, the person with disabilities could be disqualified from Supplemental Security Income benefits as well as Medicaid. Under current deeming criteria, this will occur if s/he holds assets in excess of $1,500. Finally, creditors --including the state-- may hold the person with disabilities liable for the costs of any care if s/he has any assets (Davis, 1983).

Due to these considerations, carefully worded trust arrangements have gained popularity as an alternative means of effective financial planning. Russel (1983) defines a trust as a formal agreement whereby assets are "held, managed, and owned by a person or institution (the trustee) for the benefit of those persons or organizations for whom the trust was created (the beneficiary)" (p.61). At present, such arrangements represent the most effective means of financial planning and, if properly worded, can achieve a variety of goals, such as:

- Protecting the financial eligibility of the person with disabilities for government benefits (e.g., Supplemental Security Income, Medicaid);
- Establishing a sound means for managing the money left in trust on behalf of the person with disabilities. Such money management could include investing prudently, conserving assets over the person's lifetime, paying bills, and securing goods or services as needed;
- Providing a means for parents to control the distribution of their assets even after the death of their child with disabilities; and
- Reducing taxes during the parents' lifetime(s) by shifting assets that produce income from the parents, who are likely in a higher income bracket, to the person with disabilities, who is likely in a lower tax bracket.

Numerous types of trust arrangements exist (see Russel, 1983; ARC National Insurance and Benefits Committee, 1984; Stuemke, 1984), each carrying with it specific terms to govern the circumstances and means by which assets are disbursed. Three commonly referenced trusts are:

- Testamentary trusts are established by the terms of the creator's will and go into effect at his or her death. Russel (1983) notes that these trusts are less common today than in the past but can be appropriate in some cases. They are most useful for parent's who cannot afford to establish a living or "inter-vivos" trust that requires periodic contributions. If these parents hold a life insurance policy, they can state in their wills that in the event of their death, all their assets, including proceeds from their insurance policy, will be placed in trust for the benefit of their child with disabilities;

- Inter-vivos trusts are established and go into effect during the creator's lifetime. Russel (1983) observes that they can be created with relatively small amounts of money, while the bulk of parental assets flow into the trust when the creator dies according to the terms of a will. These trusts, however, require periodic contributions from parents so that they may retain control of assets that could otherwise be tied up in the trust.

  Stuemke (1984) argues that this type trust offers at least four advantages over a testamentary trust. First, assets that flow into the trust at the parent's death are not subject to a probate fee or the time delay of probate. Second, inter-vivos trusts assure some level of privacy, in contrast to probate records. Third, it accords parents valuable time to evaluate the performance of the trustee. Finally, it can provide parents with flexibility and adaptability to future events by granting discretionary powers to others. Thus, in the event of serious illness or diminished capacity to function, parents can count on the trust continuing to operate; and

- Master or joint trusts are arrangements whereby parents pool a portion of their assets in the name of their son or daughter with disabilities with assets contributed by other parents. Because many financial institutions refuse to manage small trusts (i.e., trusts under $50,000), many parents of low to middle income cannot easily arrange an appropriate trust. Thus, master trusts serve a useful purpose by allowing parents of varying incomes to benefit from a trust arrangement. These trusts, however, represent a cooperative agreement and cannot be easily customized to accommodate the needs of individual families. As a result,

> parents are advised to examine the terms of the available trust to determine if its provisions are appropriate for their needs.

Given the number of available approaches to establishing a trust, Apolloni (1984) argues that many families require professional guidance. Such assistance could prove helpful in selecting an appropriate trust arrangement and trustee, and in preparing the trust. In response to this need, numerous specialized organizations have emerged around the country to offer professional guidance to parents with sons or daughters with disabilities. Moreover, some of these organizations have initiated master trusts, will act as trustee, or will also provide guardianship or advocacy services.

To obtain an improved understanding of this movement, the Human Services Research Institute and the National Association of State Mental Retardation Program Directors undertook a national survey of existing estate planning organizations that cater to parents who have sons and daughters with a developmental disability. The purpose of this chapter is to report the findings of this survey.

Method

Information was solicited from 50 states during a survey period beginning in November, 1983 and continuing through March, 1984. All programs profiled as a result of the survey were actively involved with administering future financial planning or trust arrangements on behalf of persons with developmental disabilities.

Programs were identified based on information collected by state directors of mental retardation across the country and other knowledgeable persons in the field. These persons were surveyed by mail for names of persons or organizations involved with estate planning or establishing trust arrangements for persons with diabilities.

Subsequently, interview guides were forwarded to any identified persons or organizations. These guides sought information in a variety of areas including: year of program initiation, corporate status, affiliate organization, number of clients served, eligibility criteria, sources of income, and services provided. In some cases, telephone inquiries were used to contact persons who failed to respond to the mailed survey or to clarify information received.

Results

Information was gathered from persons around the country describing numerous worthwhile efforts. In many cases, however, the organization described provided advocacy or guardianship services but not financial planning. These programs were not reviewed. Likewise, materials were received from other groups that offered some financial guidance but primarily provided advocacy services. It was decided to review a limited number of these advocacy-oriented programs for purposes of comparison with those primarily directed at financial planning. Thus, the full range of these programs was not profiled.

Based on these decisions, 19 programs were identified that provide systematic estate planning and/or trust arrangements on behalf of persons with disabilities. Detailed descriptive information, however, could be acquired on just 11 of these programs. Table 1 displays these 11 programs according to seven primary information areas and reveals several findings of note:

Date initiated. The oldest program profiled was begun in 1963 (Foundation for the Handicapped). Most programs, however, were initiated in the late 1970's or early 1980's.

Table 1: Eleven Financial Planning Programs by Seven Areas of Information

PROGRAM NAME	TYPE	YEAR INITIATED	AFFILIATION	SERVICE AREA	CLIENTS SERVED	ELIGIBILITY CRITERIA		SOURCES OF REVENUE
						DISABILITY CATEGORIES	OTHER	
GUARDIANSHIP ADVOCACY AND PROTECTIVE SERVICES PROGRAM OF OREGON	NONPROFIT (SUBSIDIARY)	1978	OREGON ARC	STATEWIDE (OREGON)	400 ALL SERVICES (300-350) FINANCIAL PLANNING	DEVELOPMENTAL DISABILITIES	OREGON RESIDENT	PARENTAL DONATIONS ARC FUND RAISING UNITED WAY GRANTS GIFS/BEQUESTS
PACT OF CHICAGO, ILLINOIS	NONPROFIT	1981		URBAN AREA (CHICAGO, ILLINOIS)	165 (40 GUARDIANSHIP)	DEVELOPMENTAL DISABILITIES MENTAL ILLNESS, AGED	CHICAGO AREA RESIDENT	PARENTAL SERVICE FEES GRANTS ENDOWMENT FUND
VIRGINIA BEACH COMMUNITY TRUST	NONPROFIT (SEMI-AUTONOMOUS)	1982	VIRGINIA BEACH COMMUNITY SERVICES BOARD (GOVERMENT AGENCY)	URBAN AREA (VIRGINIA BEACH, VA)	25 TRUSTS	DEVELOPMENTAL DISABILITIES	VIRGINIA RESIDENT CLIENT IN VIRGINIA BEACH AREA	PARENTAL DONATIONS LOCAL GOVERNMENT SUPPORT
STAR SYSTEMS CONSULTATION AND TRAINING	FOR PROFIT	1981		MULTI-STATE (PA, NY, NJ, KA)	NOT AVAILABLE	DEVELOPMENTAL DISABILITIES MENTAL ILLNESS AGED PHYSICAL DISABILITTIES CHILDREN	NOT APPLICABLE	PARENTAL SERVICE FEES
PLANNED LIFETIME ASSISTANCE NETWORK (PLAN) OF VIRGINIA	NONPROFIT	1984		SUBSTATE AREA CHARLOTTESVILLE, VA PROJECTED STATEWIDE	NOT AVAILABLE	MENTAL RETARDATION FUNCTIONAL INCOMPETENCE	VIRGINIA RESIDENT	PARENTAL SERVICE FEES ENDOWMENT FUND
BRIDGE FOUNDATION	NONPROFIT (SUBSIDIARY)	1981	THE MUTUAL BENEFIT LIFE ASSURANCE, CO.	INFORMATION NOT AVAILABLE	30 (ANCILLARY INCOME TRUST-65)	ANY CHRONIC DISABILITY	NOT IN A PUBLIC INSTITUTION	LIFE INSURANCE COMMISSIONS
SENTRY FUND (MICHIGAN)	NONPROFIT (SEMI AUTONOMOUS)	1974	KENT COUNTY ARC	SUBSTATE (KENT CO. RESIDENT)	60 TRUSTS	MENTAL RETARDATION	KENT CO. RESIDENT	PARENTAL SERVICE FEES KENT CO. ARC DONATIONS
INLAND COUNTIES MASTER TRUST (CALIFORNIA)	NONPROFIT (SEMI AUTONOMOUS)	1978	INLAND COUNTIES REGIONAL CENTER	SUBSTATE SOUTHERN CALIFORNIA	62 TRUSTS	DEVELOPMENTAL DISABILITIES	SOUTHERN CALIFORNIA RESIDENTS	PARENTAL SERVICE FEES
FOUNDATION FOR THE HANDICAPPED (WASHINGTON)	NONPROFIT	1963		STATEWIDE (WASHINGTON)	500 TRUSTS	MENTAL DISABILITY ANY OTHER SEVERE DISABILITY	WASHINGTON RESIDENT	PARENTAL SERVICE FEES PRIVATE DONATIONS BEQUESTS UNITED WAY
PERMANENT PLANNING INC. (IOWA)	NONPROFIT (SEMI AUTONOMOUS)	1973	EXCEPTIONAL PERSONS INC. OF SIX COUNTY AREA	SUBSTATE (IOWA STATE SERVICE REGION VII)	50 (28 GUARDIANSHIP)	DEVELOPMENTAL DISABILITIES	CLIENT OF SERVICE REGION VII	PARENTAL SERVICE FEES INCOME FROM REAL ESTATE INVESTMENTS
NATIONAL CONTINUITY FOUNDATION	PRIVATE NON PROFIT	1984		NATIONWIDE	-NONE AT PRESENT- NEW PROGRAM	DEVELOPMENTAL DISABILITIES		PROCEEDS FROM $50,000 DEATH BENEFIT PLAN MADE PAYABLE TO TRUST PARENTAL DONATIONS PRIVATE CONTRIBUTIONS

Corporate status. Only Star Systems Consultation and Training Services operates as a "for profit" organization. All other organizations have a nonprofit corporate status.

Affiliate organization. Five programs are not affiliated with any other organization. Of the six that are, two are associated with local Associations for Retarded Citizens, two with government offices, and two with a provider agency.

Service area. Only the National Continuity Foundation is available across the country. Of the remaining ten programs, one is available in multiple states, two are available statewide, four are available in sub-state regions, and two in urban areas. No information of this kind was available on the Bridge Foundation.

Number of clients. The Foundation for the Handicapped serves the largest number of clients (n=500), while the Virginia Beach Community Trust serves the fewest (n=25). (The National Continuity Foundation was just begun and presently has no clients.) These figures, however, can be misleading because the programs profiled offer services that are not necessarily comparable.

Eligibility criteria. All programs except the National Continuity Foundation have residency requirements related to the program's service area. Regarding the disability categories of clients served, all but one program specifies developmental disability as a satisfactory precondition. The exception, Sentry Fund, confines its service to persons with mental retardation. In addition, many will serve persons with other disabling conditions (e.g., mental illness, physical disability, functional incompetence, aging). Only Star Systems serves parents of children without disabilities.

Sources of income. As expected, all programs depend on the collection of fees or donations from parents as a primary source of income. In certain cases, the fees charged or the conditions set by the program place it out of the reach of many parents. For instance, the Bridge Foundation is funded through tax-deductible contributions from parents equal to the amount it costs to purchase a $250,000 life insurance policy. Monthly payments on this policy range from $235 at age 30 to $835 at age 55. Moreover, if the person with disabilities dies before the parents or the parents discontinue payment, the Foundation's obligation terminates and the accrued cash reserves remain the property of the foundation. Given these specifications, it is unlikely that many middle or low income families would have the resources to participate in this type program.

Other income sources were reported by nine programs including gifts or bequests, grants, donations from private citizens or foundations, real estate appreciation, and government support. One promising approach, developed by the National Continuity Foundation utilizes the proceeds of a specially designed $50,000 life insurance policy to fund lifetime advocacy for persons with disabilities.

This foundation has established a Master Trust to which participating parents sign a simple joinder agreement. The $50,000 policy is issued on the life of the parent with the foundation as beneficiary. After the death of the insured parent, the foundation distributes income to qualified service providers operating in the hometown of the person with disabilities to provide him or her with protection and advocacy services. The services provided are monitored by the foundation.

Table 2 displays the primary and auxilliary services offered by

Table 2: Services Offered in 11 Financial Planning Programs

PROGRAM NAME	GUARDIANSHIP	ADVOCACY	FINANCIAL PLANNING	TRUST FUNDS	MASTER OR JOINT TRUST	ADDITIONAL SERVICES
GUARDIANSHIP ADVOCACY AND PROTECTIVE SERVICES PROGRAM OF OREGON	X	X	X			
PACT OF CHICAGO, ILLINOIS	X	X				CASE MANAGEMENT INFORMATION PROGRAM ASSESSMENT SPECIAL SERVICES ESTATE PLAN REVIEW
VIRGINIA BEACH COMMUNITY TRUST				X		CASE MANAGEMENT FAMILY COUNSELING ON FUTURE NEEDS
STAR SYSTEMS CONSULTATION AND TRAINING			X			CASE MANAGEMENT TECHNICAL ASSISTANCE SPECIAL SERVICES FOR A FEE
PLANNED LIFETIME ASSISTANCE NETWORK (PLAN) OF VIRGINIA			X		X	SURROGATE FAMILY ROLE
BRIDGE FOUNDATION						MANAGEMENT OF FINANCES LIFE INSURANCE POLICY
SENTRY FUND (MICHIGAN)		X			X	CASE MANAGEMENT
INLAND COUNTIES MASTER TRUST (CALIFORNIA)					X	
FOUNDATION FOR THE HANDICAPPED (WASHINGTON)	X		X		X	ACT AS REPRESENTATIVE PAYEE LEGAL ADVICE STATEWIDE REGISTRY OF PERSONS WITH SEVERE DISABILITIES
PERMANENT PLANNING INC. (IOWA)	X		X			
NATIONAL CONTINUITY FOUNDATION	X	X	X		X	USES EXISTING LOCAL SERVICE AGENCIES TO RENDER SERVICES $50,000 DEATH BENEFIT PLAN

each program. Regarding primary services, five will assume guardianship, four provide advocacy, six offer financial planning, one will establish trusts, and seven offer master trust arrangements. Eight programs reported a primary emphasis in multiple service areas. Though the National Continuity Foundation offers no direct services, it arranges for services to be provided by contracting with existing service providers as needed.

In addition to primary services, survey results show that most programs offer a range of other services. Case management is the most commonly offered auxilliary service (four programs). Examples of other services noted include specialized services (for fee), technical assistance or information, legal advice, and financial management.

Discussion

The emergence of specialized organizations for helping parents to establish trusts in behalf of their sons and daughters with developmental disabilities is a welcome addition to the growing array of family support services. Clearly, they can help reduce the anxiety many families experience with regard to the future financial well being of their members with disabilities. The relatively recent inception of most of these organizations, however, precludes any firm conclusion pertaining to their overall efficacy. In this regard, three key issues warrant attention.

What Is the Best Way to Establish a Financial Planning Program?

Ordinarily, determining the best means of establishing a program can be distilled from review of past successful efforts. But because most existing programs in this area have only been initiated recently, few have demonstrated enduring success. Thus, existing programs offer little time-tested guidance.

As a result, those concerned with establishing financial planning or trust programs must depend on a review of relevant literature, the present experience of others, and careful consideration of numerous issues. Apolloni (1984) and the Association of Retarded Citizens of Colorado (1983) note several issues that must be examined:

- Corporate Status. What should be the organization's corporate stutus: profit or nonprofit?
- Corporate Affiliation. Should the organization act as a separate, free-standing corporation, or should it function as a subsidiary of some other established corporation?
- Board Membership. Who should serve on the board? What expertise should be represented? Should the board include persons with developmental disabilities, members of subscribing families, service providers, lawyers, trust management and investment experts? Should there be a membership outside of the board? How many people should serve on the board? What officers are needed and what should be their duties and powers? What committees are needed and what should their roles and responsibilities be?
- Board Selection. How should board members be selected (membership vote; board member vote; appointment by outside bodies such as advocacy organizations, elected officials, judges, etc.)?
- Board Responsibility and Powers. In what capacity should the board function? Should it be appointed as a guardian of its clients with disabilities or simply facilitate guardianship arrangements with volunteers as needed? What decisions must the board make and which could be delegated to staff? Should committees be established to carry out or oversee activities such as long range planning or trust investment?
- Funding. How much funding is needed to assure program stability and how will it be obtained? What sources of funds should be pursued in the long term and how should resources be allocated to secure such funds? How should the organization's services be marketed?
- Services Provided. What services should the organization provide? Should these services be provided directly or should the organization simply coordinate and monitor service provision by establishing contractual arrangements

with existing agencies to perform some or all specified service functions

- Development Timeline. What is a realistic process and timeline for instituting the corporation's program throughout its proposed geographic region? What observable milestones will be apparent to confirm that deveopmental progress is occuring in an orderly manner?

What Role Should Government Play in Assuring Quality?

Study results imply that government has played a small role, if any, in the operation of existing financial planning or trust programs. These programs generally are funded by sources outside of government and driven by parental concerns. But it must be understood that these organizations are often entrusted with overseeing the habilitative services provided by the state and that several organizations hold substantial parental assets on behalf of persons with disabilties. The seriousness of these responsibilities raise questions regarding the competence and long term stability of these programs. There is, therefore, a need to ensure the integrity of these private guardianship and financial planning programs over time.

Programs offering advocacy or guardianship services are positioned to press service providers and the state to provide the most appropriate habilitative services for their clients. But who determines what is in the client's "best interest?" In contracting with a given program, parents presume that the staff will combine contemporary habilitative knowledge with genuine concern for their child or adult. But the ability to meet these expectations varies by program. Thus, to protect the long term interests of parents and their sons and daughters with disabilities, establishing some type of standardized quality assurance mechanism will be neccesary.

Similarly, when establishing trust arrangements, parents presume that their assets are safe from unforseen loss. This may be true in nearly all cases but the possibility exists that the terms of a trust or the organization administering a trust could fail. This could occur if a trust is not properly prepared or through organizational mismanagement. Ordinarily, the enduring success of a program could be taken as proof of its potential for long term stability and effectiveness. The newness of so many financial planning and trust programs, however, does not allow parents to judge programs based on their past performance and leaves them vulnerable. Thus, there may also be a need to safeguard parental assets against loss due to mismanagement or fraud and/or to develop standards for establishing sound and effective trusts.

The role government should play, if any, in addressing these and similar issues is open to discussion. Some argue that because the state has a long term interest in the well-being of its citizens with disabilities, it should establish standards or regulations to govern financial planning and trust initiatives. Others argue that government should steer clear of these programs because public money is not often involved, government has a conflict of interest due to its role as service provider and funder, and involvement might result in states being held liable for any financial losses incurred by parents.

Adminstrators of financial planning and trust programs may do well to establish their own commonly accepted quality assurance formats. Other organizations facing similar issues have shown that such systems can be developed and have some effect on programs (Human Services Research Insitute, 1984). Examples include the Commission on Accreditation of Rehabilitation Facilities (CARF) and the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC-MR/DD). To the extent that such forums can be established, the need for government regulation in this emerging industry can be avoided and the interests of parents and their sons and daughters with disabilities will be better served in the long term.

What Place Does Financial Planning Have in the Service Continuum?

There is a growing interest among states for improving the quality and range of services available to families who have members with a developmental disability (See Part II; Chapter 3). None of these family support services, however, offer comprehensive financial planning guidance or trust arrangements. Thus, the emergence of programs designed to provide such services is a welcome addition to the overall service continuum.

Because these programs receive no public support, however, they stand outside the traditional service network. Consequently, some consideration must be given to effect that these services may have on the human services field. On the client level they can have a positive effect because they can act as a powerful advocate on behalf of individual clients. This is especially true of programs that render formal guardianship and advocacy services. Because such programs administer multiple cases, they will be positioned to press for more equitable distributions of services among clients. For instance, given two clients with similar disabilities and functioning levels, a corporate guardianship and trust organization could vigorously object if one were placed in an institution and the other in a community group home.

Similarly, on a systems level, a financial planning and trust program could have a significant impact on the substance and course of services in an area. This could occur if the program assumed guardianship responsibilites for numerous clients and/or held significant amounts of assets in their behalfs. Given these conditions, programs could broker with the state and provider agencies to provide the type and amount of services needed to serve all clients in an area. Of course, the more clients a program served, the greater its influence could be.

Additionally, it must be understood that these programs presume that parents have resources available to invest in the future well-being of their son or daughter with a disability. For numerous families of middle or low income, however, this will not be the case. Moreover, families of any income who are faced with extraordinary costs related to providing care may be incapable of investing in financial planning programs. Thus, while these programs will be useful to some families, many will be unable to participate due to insufficient resources.

Though the above issues are particularly relevant to those concerned with establishing worthwhile financial planning mechanisms, the future viability of such programs will be determined by how effective they are in the long term. Due to the recent inception of most specialized financial planning programs, however, no longitudinal perspective is available. Consequently, assessing the efficacy of various means for capitalizing assets to provide future benefits for program enrollees is a difficult process. Take, for example, the Sentry Fund, established ten years ago. Currently, only two trusts are considered activated as a result of parents' deaths.

The money and effort required to provide services for these two clients is far less than what may be required to meet the similar needs of perhaps 10-20 additional participants in ten years. Thus, the capacity of this organization to fulfill its functions will not be tested truly for several years.

Compounding matters are the multiple models that currently exist to provide financial planning services. Such flexibility allows programs to be organized in ways that are thought to be most efficient and responsive to parental concerns. Significant variance in program design, however, makes comparison between programs more difficult and hinders the emergence of any consensus among professionals regarding the most effective approaches.

These conditions suggest that efforts to initiate and provide financial planning services must be complemented with systematic evaluation of their short and long term effects. With such information, program administrators can begin integrating the most effective practices into their programs. Moreover, standards for assuring the quality of estate planning services will be more easily determined and applied. To the extent these aims are accomplshied, parental concerns over the future well being of their son or daughter with disabilities will be further alleviated.

USING TAX POLICY IN SUPPORT OF FAMILIES WHO HAVE A MEMBER WITH DEVLOPMENTAL DISABILITIES

Current financial supports for many families who have members with developmental disabilities are insufficient. In response, several policy options have been suggested for complementing existing family support programs, including modification of state and/or federal tax policy. The primary intent of such policy would be to provide parents with a financial incentive for caring for their offspring with developmental disabilities at home. The purpose of this chapter is to: 1) examine the various modifications of tax policy that could be made; 2) review what tax incentives presently exist on the federal and state levels; and 3) offer discussion pertaining to the use of tax policy for supporting families.

Potential Tax Policy Options

Though federal and state tax policy can be altered in a number of ways, attention has centered on three basic policy options: tax exemptions, tax credits, and specialized tax relief.

Tax Exemptions

Tax exemptions allow reductions in the taxpayer's taxable income. The amount of the reduction can be standardized or can fluctuate up to some maximum limit depending on the taxpayer's costs providing care to a dependent with disabilities. In addition, to offset the costs of care, Piccione (1982a) suggests that tax exemptions could be used in at least two other ways.

First, one parent could be offered a standardized deduction for remaining at home to provide care. If used in tandem with post hoc exemptions related to the real costs of care, this of type exemption can act as an affirmative means of encouraging family-based care. Though for many families this approach will have little effect because both parents desire to pursue careers, for others such an exemption may make it possible -- and preferable -- for one parent to forego employment in favor of providing family-based care.

Second, Piccione (1982a) suggests that volunteers could be provided with tax exemptions based on the amount of time spent in assisting families with disabled relatives. When combined with existing respite care programs, this type of incentive to volunteerism could further ease the burdens of family-based care.

Tax Credits

Tax credits refer to reductions in the taxpayer's calculated tax liability. The credit amount can be standardized or may fluctuate according to several criteria related to the costs of care. Moreover, it can be thought of as either refundable or non-refundable. Refundable tax credits allow taxpayers to receive a refund of any amount of the credit that is in excess of their tax liability. Non-refundable tax credits do not allow the taxpayer to recoup the excess, and therefore fail to accommodate low-income taxpayers who have no tax liability but might otherwise be eligible (GAO, 1982).

It should be noted that both of the suggestions offered by Piccione (1982a) with regard to tax exemptions could be thought of in terms of tax credits. That is, both homemakers and volunteers involved with the provisions of family-based care could be offered tax credits as partial compensation for their efforts.

Specialized Tax Relief

This category refers to tax relief options not directly pertinent to income-related tax structures. Tax relief can be provided through exemptions or credits for a variety of taxes including real estate or property taxes, sales tax, taxes on investment dividends and interest, and excise taxes for telephone usage. In addition, as discussed below, special Individual Retirement Accounts (IRA) established for the benefit of a family member with disabilities would also fall into this category.

Present Federal Level Tax Policy

At present, the federal government offers several mechanisms for caregiving families to reduce their tax liability. Four such options are: deductions associated with reporting income, tax credits for child and dependent care expenses, employer related flexible spending accounts, and Individual Retirement Accounts.

Standard Deductions

When computing one's income the Internal Revenue Service allows several expenses to be exempted from the income of persons with disabilities or their parents. These deductions, however, are not always available to *all* persons with disabilities; several are restricted to specific disability categories (e.g., blind, deaf, physical disabilities). The Office of Information and Resources for the Handicapped (1983) notes the following allowable deductions:

- Special equipment such as motorized wheelchair, special equipped automobile, and special telephone for deaf persons;
- Special items, including artificial teeth, artificial limbs, eyeglasses, hearing aids and their component parts, crutches, and dogs for blind or deaf persons;
- The cost and repair of special telephone equipment that enables a deaf person to communicate effectively over a regular telephone by means of converted teletype signals;

- Payments for the installation of special equipment in the home or for similar improvements made for medical purposes, such as ramps or elevators for heart patients. (If these improvements increase the value of the property, expenses incurred will only be deducted to the extent that they exceed the increase in property value.);
- Payments to a special school for persons with mental or physical handicaps, if the principal reason for attendance is the institution's resources for alleviating the handicap; and
- An additional personal exemption over and above the one claimed by everyone may be taken by blind persons.

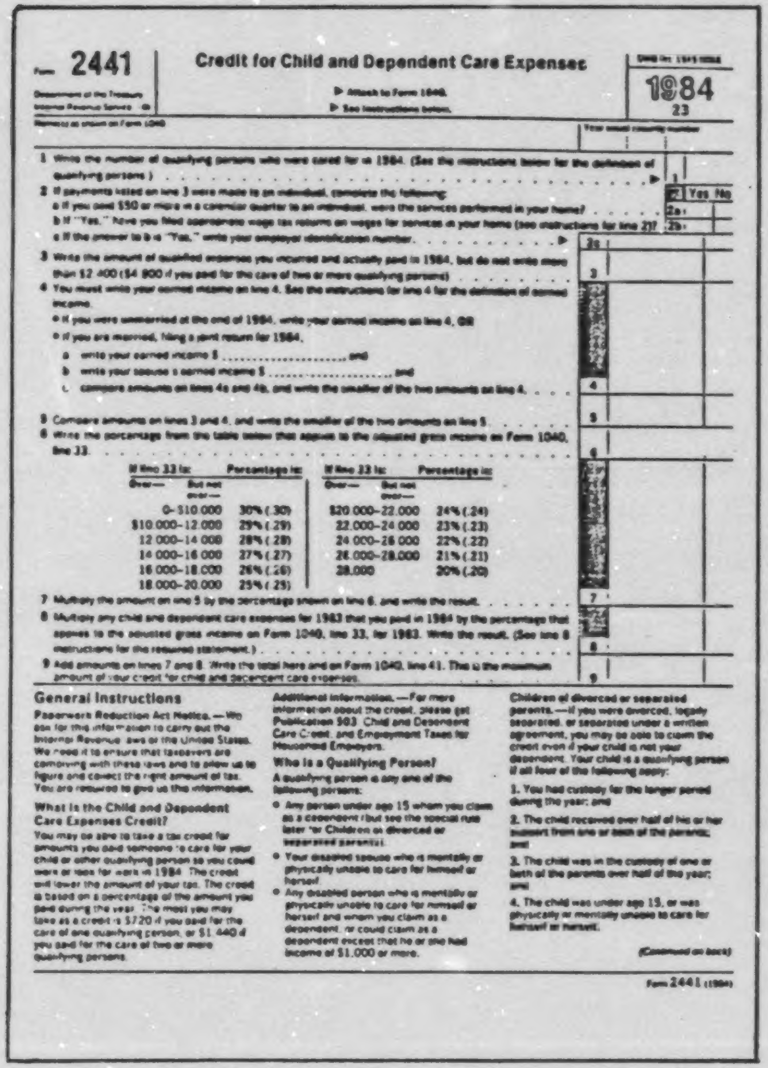
Credit for Child and Dependent Care Expenses

The General Accounting Office (GAO)(1982) reports that the most useful federal tax program for assisting caregiving families is the "child and dependent care tax credit," initiated in 1954. Its original purpose was not to ease the burden of providing family-based care, but to enable family members to gain employment. Since then, Perlman (1983) notes that several other reasons for the program have emerged, including: promoting the hiring of domestic workers, encouraging family-based care, providing relief to middle and low income groups, and providing relief for needed dependent care services.

As shown in Figure 1, a non refundable tax credit for child and dependent care expenses can be claimed for up to $2,400 for each of two qualifying dependents. However, when the amount claimed is considered in relation to parental income the allowed credit is adjusted according to a percentage formula. The most that can be taken in credit is $720 per qualifying person. Those expenses that may be claimed include household services (e.g., services of a cook, maid, babysitter, cleaning person) if the service was partly for the care of the qualifying person, care to assure the well-being and

BEST COPY AVAILABLE

Figure 1: Form Used to Claim Tax Credit for Child and Dependent Care Expenses



Form 2441

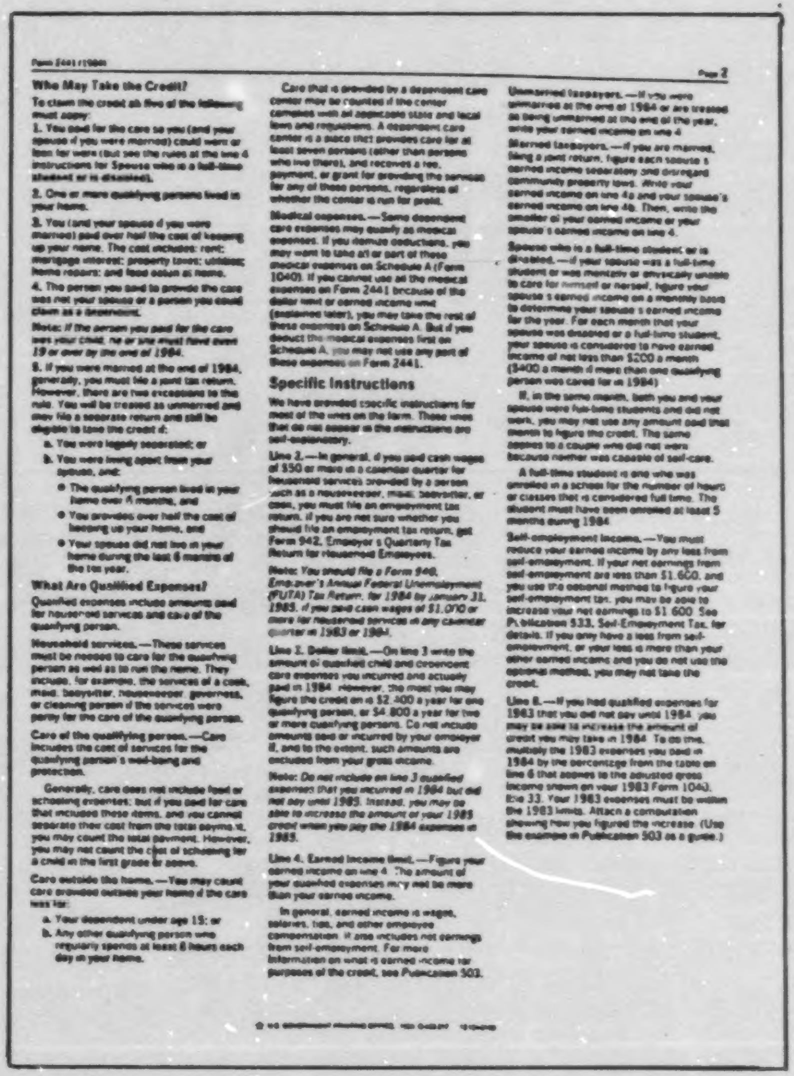
Credit for Child and Dependent Care Expenses

1984

23

If line 33 is: Over—	But not over—	Percentage is:	If line 33 is: Over—	But not over—	Percentage is:
0	$10,000	30% (.30)	$20,000	22,000	24% (.24)
$10,000	12,000	29% (.29)	22,000	24,000	23% (.23)
12,000	14,000	28% (.28)	24,000	26,000	22% (.22)
14,000	16,000	27% (.27)	26,000	28,000	21% (.21)
16,000	18,000	26% (.26)	28,000		20% (.20)
18,000	20,000	25% (.25)			

General Instructions



Who May Take the Credit?

What Are Qualified Expenses?

Specific Instructions

protection of the qualifying person, costs of care outside the family home (e.g., day care center), and certain medical expenses.

A qualifying child or dependent is any one of the following:

- Any person under age 15 who can be claimed as a dependent (there is a special rule concerning children of divorced or separated parents);
- A disabled spouse who is mentally or physically unable to care for him or herself; or
- Any person with disabilities who is mentally or physically unable to care for himself or herself and who is claimed as a dependent or could be claimed except that s/he earned $1,000 or more during the tax year.

To claim the credit, the taxpayer must have:

- Paid for the expenses claimed to allow both parents to work or look for work (certain rules apply for a spouse who is a full time student or has a disability);
- One or more qualifying persons living in his or her home;
- Paid over half the cost of keeping up his or her home. This cost includes: rent, utilities, mortgage interest, property taxes, home repairs and food eaten at home;
- Filed a joint tax return, if married by the end of the fiscal year. Exceptions to this rule apply if the married couple was legally separated or if the taxpayer lived apart from his or her spouse, and 1) the qualifying person lived in the taxpayer's home for over six months, 2) the taxpayer provided over half the cost for keeping up his or her home, and 3) the taxpayer's spouse did not live in the home for the past six months of the tax year.

In addition, it should be noted that credit cannot be claimed for services rendered by a dependent or spouse of the taxpayer. Moreover, if the person paid for providing care is a child of the taxpayer, s/he must have been 19 years of age or older by the end of the tax year. Thus, the cost of care provided by non-dependent relatives of the taxpayer (egs., grandparents, aunts, uncles) can be claimed.

It is difficult to estimate the number of families caring for persons with developmental disabilities who have claimed this credit.

The primary reason is that taxpayers providing care to dependent persons without disabilities are also eligible for the credit and their numbers are not distinguished from those providing care to persons with disabilities. Perlman (1983) writes that he pursued this matter with the Office of Tax Analysis (in the Office of the Secretary of the Treasury) and was advised that when reviewing aggregated summary statistics that "10% of the expenses claimed and 10% of the tax credit be attributed to home care and 90% to child care" (p. 281).

Based on this advice, Perlman (1983) estimates that: 1) the number of families who have members with disabilities who claim this credit has risen from about 100,000 before 1971 to 300,000 in 1978; 2) the combined expense claimed by families increased from $125 million in 1973 to $263 million in 1977; 3) the average amount claimed per family during the years 1971-1977 ranged from $700 to $1400; and 4) the loss in tax revenue rose from about $18 million before 1971 to $66 million in 1978.

These figures, however, must be interpreted with caution because they are based on rough percent estimates of families providing care to members with disabilities. If taken on face value, however, at least three observations can be made:

- Comparing the number of families claiming the tax credit (around 300,000 in 1978) with estimates of the prevalence of family-based care, it can be concluded that relatively few families take advantage of this tax credit option. Perlman (1983) estimates that under 10% of those eligible claim the credit. Reasons for this surprisingly low estimate are unknown. It can be speculated, however, that: 1) requiring taxpayers to obtain and complete additional tax forms may deter some from taking advantage of the program, and 2) many parents may be unaware of the program.

- The dollar amounts claimed by all families for care averages between $700 to $1400. If this range is an accurate representation of expenses claimed by families who have children with developmental disabilities, then it is surprisingly low. In part, this may be because of the restrictive criteria for claiming the tax credit. Much of the care provided within the home may be provided by other live-in family dependents (e.g., siblings) and cannot be claimed. If this type of unpaid -- yet often extraordinary -- care were allowable, the dollar amounts claimed likely would increase dramatically.

- Several authors (e.g., Perlman, 1983; Surrey, 1973) have argued that the tax credit program is inequitable because it favors higher income families. The program is not easily accessible to those of low income because it is fundamentally designed for married persons who are employed on or nearly on a full-time basis or for single persons to enable them to gain employment. Those who are retired, unemployed or ignorant of the program do not benefit.

Flexible Spending Accounts

A flexible spending account is a type of "Cafeteria Benefit Plan" (See the Tax Reform Act of 1984; Section 125) where employers offer workers choices among cash or fringe benefits that are excludable from gross income. Money placed in this type of an account by an employee is not subject to federal, state or social security (FICA) tax. Thus, employees are provided with a means of reducing their tax burden, thus freeing income for covered expenses. Of course, government is absorbing part of the costs of such benefits through a reduction in the tax base.

There are two types of flexible spending arrangements:

- Benefit bank accounts where the employee generally allocates a specified portion of his or her monthly salary to a reimbursement account for certain benefits such as medical, legal or dependent care expenses at the beginning of the plan year. The money set aside is subsequently used to reimburse the employee for covered expenses incurred over the year. At the end of the plan year, unspent allocations are either carried over to the next plan year, returned to the employee as taxable income, or forfeited and used by the employer to administer the program; and

- Zero balance reimbursement accounts or "ZEBRA" arrangement where employee income generally is not specifically allocated to an account at the onset of a plan year but rather is allocated only after a covered expense is incurred. Usually, the employee is reimbursed by the employer by subtracting the total amount of covered expenses from the employee's taxable income at the end of the tax year.

Because flexible spending accounts require that an agreement be reached between the employer and employees regarding the nature of the account, these arrangements vary by worksite. In general, however, the following conditions apply:

- Any employee eligible for benefits qualifies to arrange a flexible spending account. There are, however, restrictions placed on "highly compensated employees" such as those who: act as an agency officer during the plan year or any of the four preceding plan years, are one of the ten employees owning the largest interest in the agency, own five percent of the agency, or own one percent of the agency and earn more than $150,000 per year;

- The flexible spending arrangement can cover a variety of expenses including certain legal expenses, medical/dental expenses (e.g., vitamins, drugs, visits to medical doctors, dentists, physical therapists, psychiatrists), rehabilitative aids (e.g., eyeglasses, contact lenses, crutches, false teeth, braces, hearing aids), transportation services associated with obtaining medical care, and expenses for providing care to a dependent child under age 15 or person with disabilities who is incapable of self care (e.g., day care, sitter services). There is no maximum limit for expenses incurred, though individual employers may set limits.

- Reimbursed expenses cannot be claimed elsewhere by the employee with the intention of further reducing his or her tax liability. For instance, the taxpayer cannot be reimbursed for dependent care expenses as part of a flexible spending arrangement and then use the expense to participate in the tax credit for child and dependent care program;

- The employer assumes the costs associated with administering the flexible spending program. However, some of these costs are offset because: 1) employers may place the money allocated to the program by employees into a bank account that earns interest for the employer, and 2) the amount of social security tax (FICA) paid by the employer for workers participating in the program is reduced. This occurs because the each worker's gross taxable income is reduced commensurate with the amount he or she allocates to the program;

- Employers maintaining a flexible spending arrangement are required to file a return showing: 1) the number of employees of the employer, 2) the number of employees participating in

> the plan, 3) the total cost of the plan during the year, 4) the name, address, and tax payer number of the employer, and 5) the type of business in which the employer is involved. The Secretary of the Treasury plans to issue regulations governing how and when this return should be filed.

Flexible spending accounts appear to be a useful way for workers to stretch the purchasing power of their earnings. The utility of this type program for workers who have family members with disabilities is obvious. However, little is known presently about the number or nature of flexible spending accounts in operation or of their effects on families, businesses and government revenue. The Tax Reform Act of 1984, however, specifies that the Secretary of Health and Human Services, in cooperation with the Secretary of the Treasury, must evaluate the effects of all types of cafeteria plans on the containment of health care costs and to determine what modifications could be made to the rules governing cafeteria plans to enhance their effects.

As noted in the discussion of tax credits, the cafeteria plan tends to provide the most benefit to those in the higher tax brackets. For example, for those in the 50% bracket, any reduction in taxable income results in a 50% reduction in tax liability and means that the U.S. Treasury is a major source of subsidy for covered expenses. In contrast, for those in the 20% bracket, the benefits of such a plan and the burden on the treasury are significantly lower.

Individual Retirement Accounts

Recent liberalization of regulations governing IRAs is intended to encourage wage earners to set money aside for the future benefit of themselves and a non-working spouse. At present, there are no provisions for using IRAs to benefit any other non-working dependent, such as a family member with disabilities. (In 1981 the National Association for Retarded Citizens proposed to Congress that a provision be adopted to permit parents to establish an additional account for their offspring with disabilities, but it was not passed.)

Based on changes in tax laws adopted in 1982, Boggs (1984) suggests that there are at least two ways for parents to use an IRA to benefit their offspring with disabilities. First, if a parent already possesses a sufficient retirement plan, s/he can set up an IRA in the name of the person with disabilities, deposit up to $2,000 per year to the account, and name the person with disabilities as a beneficiary at the death of the parent. Second, while the parent(s) help pay for daily living expenses, the person with disabilities could establish his/her own IRA account.

Though reasonable, using IRAs can be problematic for at least three reasons. First, by establishing arrangements whereby the person with disabilities is granted a sum of money later in life, s/he inadvertently may forfeit eligibility to federal entitlement programs such as Supplemental Security Income (SSI) and Medicaid or may be held liable for the costs of care provided by the state (Davis, 1983; Russel, 1983). As a result, long-term costs of care may soon deplete whatever savings were set aside. To avoid this undesireable consequence, Boggs (1984) suggests that parents make arrangements to have assets maintained in the IRA transferred into a trust account at the death of the IRA contributor. A carefully worded trust account will hold and disburse funds in the name of the person with disabilities without risking loss of federal benefits or being held liable for services received. (See Part III; Chapter 2)

Second, numerous parents will be unable to establish IRA accounts of any kind to benefit their offspring with disabilities simply because they do not have enough money to set aside. This is especially true of low and middle class families living in areas where few free family support services are available and/or when the financial costs incurred by parents while providing care are extraordinarily high. Thus, the utility of any type of IRA provision will be confined to the wealthier segments of the population and/or to parents with children that do not require expensive specialized care. Thus, a preferable strategy for parents with limited funds involves the puchase of a life insurance policy that requires modest periodic contributions. When activated, resulting assets can be transferred into a trust account in the name of the person with disabilities. One agency that sponsors this type of program is the National Continuity Foundation (See Part III; Chapter 2).

Finally, it must be understood that IRAs do little to ameliorate existing problems but are meant to help assure the future well being of persons with disabilities. But numerous families are not as concerned with the distant future as they are with the present. Such families often have a substantial need of services designed to support their present efforts. Thus, the absence of comprehensive services to accommodate existing day-to-day service needs will likely compromise the utility of IRAs for supporting family efforts.

State Level Tax Policy

There has been little examination of the role of state level tax policy in encouraging family-based care for persons with disabilities. The most complete analysis available is a 50-state survey sponsored by the North Carolina Council on Developmental

Disabilities (Edwards & Mandeville, 1982). In this study, directors of state councils on developmental disabilities, protection and advocacy agencies and departments of revenue were queried to determine: 1) which states provided an exemption on state income tax for a disabled person, 2) whether a given exemption is based on the severity of the disability or on a specific disability category, and 3) the amount of a given exemption. Survey results are not fully applicable to families who have members with developmental disabilities because the information obtained does not distinguish clearly between exemptions that can be claimed by disabled taxpayers, taxpayers with disabled dependents, or both. Moreover, no clear distinction is made between tax exemptions claimed on the basis of developmental disabilities and those stemming from other disabling conditions. In addition, the authors note that caution is warranted in interpreting survey findings because the information may be dated and/or not fully reliable. Though these limitations are worth noting, the survey resulted in several instructive findings:

- Seven states do not have a personal income tax. These states include:

    Alaska
    Nevada
    South Dakota
    Tennessee
    Texas
    Washington
    Wyoming

- Three states do not have a personal income tax, but provide exemptions for persons with disabilities on other types of state tax. These states are listed below:

    - Connecticut: provides limited exemption by category of tax (e.g., telephone).

    - Florida: provides exemptions on property tax.

    - New Hampshire: taxes real estate and income earned through interest and investment dividends. Some persons with disabilities receive exemptions on these taxes.

- Fourteen states have a personal income tax, but do not allow exemptions for persons with disabilities. These states are:

  Alabama
  California
  Iowa
  Kentucky
  Louisiana
  Minnesota
  Nebraska
  Ohio
  Oklahoma
  Rhode Island
  Pennsylvania
  Virginia
  West Virginia
  Wisconsin

- Seven states conform to the federal income tax code with regard to personal exemptions. These states are:

  Idaho
  Illionis
  Kansas
  Maine
  Missouri [with slight modifications]
  New York
  Vermont

- Nineteen states allow for some type of tax provision for persons with disabilities. These states are:

  Arizona
  Arkansas
  Oregon
  New Jersey
  Massachusetts
  Georgia
  Hawaii
  Indiana
  Colorado
  South Carolina
  New Mexico
  Michigan
  Mississippi
  Montana
  Maryland
  Delaware
  Utah
  North Carolina

- Among the 19 states with some type of tax provision, Edwards & Mandeville (1982) show that:
  - Substantial variance exists regarding the type(s) of disability that qualify for a given exemption.
  - The disability category that qualifies most frequently for an exemption is blindness (15 states). The next most frequent category is mental retardation (4 states).
  - The type of tax provision offered by states varies. Examples include tax credits, home exemptions, and rebates on property tax.

The results presented above indicate that several states recognize that tax policy can be used to ease extraordinary financial difficulties due the provision of family based care. Further, the variance between existing programs suggests that tax policy is a flexible tool that can be blended into existing state tax structures. These survey results, however, do not offer evidence regarding the overall utility of various state tax policies. What is needed is additional information that: 1) separates taxpayers with disabled dependents from taxpayers with disabilities, 2) distinguishes between disabling conditions (e.g., developmental disabilities, physical handicaps), 3) shows how often available tax options are used, 4) specifies the dollar costs to the state for a tax program in terms of administrative costs and lost revenues, and 5) sheds light on the benefits accrued by those who make use of available tax options. Based on this type of information, initial conclusions can be drawn regarding the relative utility of various tax policy options. Moreover, the role of state tax policy in the greater scheme of publicly sponsored family support can be more easily determined.

Relevant Issues

Review of current federal and state tax policy reveals that several options exist for families who have members with disabilities to reduce their tax liability. Moreover, it is clear that existing tax codes could be further modified to ecourage familiy based care. Examples include:

- Extending the double exemption pertaining to the calculation of federal tax liability to disabilities other than blindness and to taxpayers who claim a dependent with disabilities;
- Modify present rules governing use of the dependent care tax credit by increasing the amount of the credit, allowing care provided by other dependents of the taxpayer who are under age 19 to be claimed as an expense, and making it "refundable" to increase its utility for low income families;
- Expand specialized tax relief programs (egs., reduce or eliminate sales taxes on care related purchases made by qualifying parents, reduce or eliminate property taxes incurred by caregiving taxpayers);

- Permit parents to establish an IRA for their offspring with disabilities in addition to one for their own benefit; and
- Provide a tax credit to persons who assist caregiving families by providing periodic care to the family member with disabilities.

The primary issue underlying these alternatives, however, is not if incentives for family based care can be provided through the tax structure, but whether such incentives are efficient, effective, and equitable (Roberts, 1983).

At first glance, utilizing tax policy to encourage family based care seems an attractive strategy. Providing mechanisms for parents to reduce their tax liability by investing in long term family care for their offspring would likely encourage such care. Moreover, use of the tax system to support families give more freedom of choice to individual families and reduces the need for a more bureaucratic response. In essence, tax structures that permit parents to pay less in taxes amounts to a publicly financed cash assistance program for caregiving families.

Upon closer inspection, however, using tax policy in support of families may not offer the most desirable means for encouraging family care, given the following potential complications:

- Coordination between Federal, State and Municipal Level Tax Systems. Governments at various levels can initiate tax policy. Care must be taken to assure that tax structures do not conflict, but work together to maximize positive effects on the provision of family-based care;
- Enforcement of Regulations. Some concern has been expressed regarding the potential misuse of tax relief programs (GAO, 1982). Consequently, eligibility criteria must be established to assure that only those deserving of and in need of tax relief will be accommodated. Such criteria can reflect some consideration of the type of care provided by families, the severity of disability of the dependent family member, and the level of family income. In addition, effort

must be made to monitor the use of existing programs, uncover abuses, and recommend improvements in the program;

- Cost. The GAO (1982) notes several difficulties with estimating the costs (i.e., administrative costs and lost revenue) of tax relief programs. These difficulties include uncertainties regarding: 1) the number of taxpayers who will use the programs, 2) the prevailing eligibility criteria, 3) the mechanisms put in place to reduce misuses of the programs, and 4) the provisions that place limits on the dollar amounts taxpayers can gain from using a given program. Consequently, tax relief programs should be pursued with caution since other means of promoting family-based care may be more cost efficient and effective, such as providing families direct cash assistance or access to a comprehensive array of free supportive services (Michigan House Legislative Analysis Section, 1983);

- Evaluation of the Effects of Tax Relief Programs. The ongoing evaluation of the effects of tax relief programs on the capacity of families to provide care is crucial for determining the efficacy of such programs. This suggests that governmental tax analysts should coordinate with those providing other types of family support to collect information that will be of use to all concerned parties. In this way, systematic and longitudinal evaluation of all family support efforts can be pursued with the intent of enhancing the entire family support system.

- Equity. When tax policy is proposed as a means of supporting families, its utility for benefiting all types of families must be considered. A policy that benefits only certain types of parents (e.g., upper income, employed), does little to contribute to an effective national strategy for encouraging family-based care. This point grows especially salient in view of evidence showing that a significant number of families who have a member with developmental disabilities have lower incomes than the general population. In fact, Robert Perlman (See Part III; Chapter 6) shows through analysis of information collected during the 1976 Survey of Income and Education that 45% of those families providing care to persons with developmental disabilities had incomes below $10,000 in 1976, compared with 33% of all United States families; and

- Ease of Use for Families. Parents providing care to persons with disabilities cannot and should not be expected to keep abreast of the array of tax saving strategies available at various levels of government. Recall that providing care to persons with developmental disabilities is not an altogether easy task, given the potential effects of such care on the family, the ongoing needs of the person with disabilities, and the effort that must be exerted to obtain and/or participate in available services. Government officials concerned with promoting family care should be commited to simplifying the

> activities families must undertake to receive needed assistance. Certainly, tax policy can act as an incentive to family care. The presence of numerous mechanisms for reducing tax liability, however, does not guarantee that they will be utilized, especially if the strategies emerging from such policy needlessly complicates the matter of acquiring needed services.

A fundamental objective of family care policy should be to identify efficient, effective, and equitable strategies for equipping families to obtain or provide appropriate care. It should be understood from the onset that reducing parental tax liability is akin to providing parents with publicly financed cash assistance. This being the case, government officials must decide if the most desirable means for providing such assistance is through tax policy. Review of existing and potential tax incentives suggests that tax policy could be used to encourage familiy based care. It is equally clear, however, that the concept has several crucial shortcomings that severely compromise its overall utility.

Moreover, the growing commitment of states to establish family support systems further complicates matters. In effect, if government were to pursue both tax policy and statewide service systems in support of families, it would be faced with three unenviable tasks:

- Resolve issues pertaining to establishing fair and effective tax structures that coordinate the policies of multiple levels of government;
- Resolve issues pertaining to establishing a fair and effective system of family support services; and
- Determine how the resulting "two track" system for accommodating family needs could be effectively coordinated, implemented, and evaluated.

These considerations suggest that though using the tax system to support families may benefit some families, it will not be sufficient nor may it be necessarily or desirable. Program planners may well prefer to encourage and support familiy efforts through more explicit approaches that delineate the role of government more clearly, treat families more equitably, and provide support in a more systematic fashion.

USING PRIVATE SECTOR RESOURCES TO SUPPORT FAMILIES WHO HAVE A MEMBER WITH DEVELOPMENTAL DISABILITIES

Much recent discussion regarding funding for human services has focused on utilizing private sector resources (Meyers, 1982). Business and industry can get involved in the initiation of programs to support families in a variety ways. For instance, businesses can make financial contributions directly to existing service providers. Citibank/CitiCorp has pursued this course by granting $50,000 to the Metropolitan Child and Family Support Program (MCFSP) in Baltimore, Maryland (NASMRPD, 1984). With these funds, MCFSP provides services to families with children with disabilities from birth through seven years that accommodate socio-emotional, parent training, medical, and specialized programming needs.

The private sector can also initiate family support programs that are independent of existing public sector services. This can be achieved by: 1) involving segments of the for-profit service industry with family support efforts, and 2) prompting individual employers -- or organized labor unions -- to initiate services that benefit their workers who provide care to family members with developmental disabilities. The purpose of this chapter is to examine the utility of these two alternatives and to discuss relevant issues pertaining to private sector involvement in family support.

Family Care and the For-Profit Sector

Numerous for-profit businesses are in a position to support families who have relatives with disabilities. For example, banks can initiate special low-interest loans to qualifying families for special habilitative equipment or housing adaptations. Likewise, day care centers can offer specialized care for persons with disabilities. The industry that could have the greatest positive impact on families, however, is the health insurance industry.

Health insurance coverage for the long-term health care expenses incurred by many families providing care to relatives with disabilities is inadequate (Gliedman & Roth, 1980). At present, there are three basic options available to help defray these costs: Social Security Disability Benefits (SSDI), Medicaid benefits, and private insurance plans.

Social Security Disability Benefits (SSDI)

This federally sponsored insurance program is not based on a determination of family need. Instead, under this program "the child of a worker entitled to retirement, disability, or survivor's benefits can collect benefits based on the parent's earning record provided that the child's disability began before the age of 22, the child is unmarried, and the child is dependent upon the worker for support" (Davis, 1983, p. 499). Recipients of benefits are in turn eligible for Medicare. Thus, the individual with a developmental disability need not have worked and earned Social Security to become eligible for benefits.

The Medicare program has two parts:

- Part A: Hospital Insurance. This program pays for care while the participant is in a hospital or skilled nursing facility, or is receiving medically necessary home health care (e.g., visiting nurse, physical or speech therapy). There are limits on the amount Medicare will pay and the program requires that participants pay a deductable or co-pay for certain expenses. Thus, many Medicare participants elect to supplement Part A with private health insurance or the Part B Medicare program; and

- Part B: Medical Insurance. This program helps pay for doctor's bills and other health services not covered or covered only in part under the terms of Part A (e.g., home health visits, physical therapy, speech pathology, outpatient hospital services, X rays, laboratory tests, certain ambulance services, purchase or rental of medical equipment). If a person is enrolled in the Part A program, she or he automatically is enrolled in Part B -- but participants can elect to terminate their enrollment in Part B. In 1984 participants in the Part B medical insurance program were required to pay a basic premium of $14.70 a month.

Though the Medicare program offers numerous useful services, its utility for families who have members with developmental disabilities is severely limited. To qualify parents must themselves be eligible for retirement, disability or survivor's benefits under the Social Security Act. Relatively few parents, however, satisfy this eligibility standard, requiring that other means for obtaining health care coverage be considered.

Medicaid Benefits

Medicaid is a joint federal and state program available in all states but Arizona that provides physical and related health care services. Persons eligible for Medicaid are classified into three groups:

- Categorically needy: These persons receive or are eligible to receive Aid to Families with Dependent Children (AFDC). In addition, recipients of Social Security Income (SSI) generally are eligible. (Those who reside in Guam, Puerto Rico, or the Virgin Islands can qualify for Medicaid if they receive Old Age Assistance, Aid to the Blind, Aid to the Permanently and Totally Disabled, or Aid to the Aged, Blind, and Disabled.);

- Medically needy families: These persons have an income high enough to disqualify them from receiving public assistance, but who could not meet their basic needs in order to pay their medical bills. These persons can become eligible for Medicaid if they pay a premium (usually a nominal fee) and have an income that is less than the "state standard." This standard varies by state; and

- Medically needy children: persons 21 years of age or under who qualify on the basis of financial eligibility but do not qualify as a dependent under the state's AFDC plan.

Services provided under the Medicaid program could include:

- -inpatient hospital services
- -laboratory services
- -skilled nursing facility services
- -voluntary family planning
- -private duty nurses
- -dental services
- -speech therapy
- -prescribed drugs
- -rehabilitative services
- -outpatient hospital services
- -diagnosis and screening
- -physician's services
- -home health services
- -clinic services
- -physical therapy
- -occupational therapy
- -prosthetic devices

Specific eligibility requirements and types of services offered are determined by state programs of public assistance on the basis of broad federal guidelines, resulting in geographic differences in eligibility standards and available services.

Because this federally sponsored insurance program is means tested, it has, for years, acted as an incentive for middle income families to plave their members with disabilities out of the home in order to qualify them for benefits (See Part I; Chapter 1). Under present deeming rules, the income of parents is treated as though it were available to the Medicaid applicant as long as s/he is living with the family (and until s/he reaches 18 years of age). If the level of parental income and resources surpasses the means test for eligibility, the person with disabilities does not qualify for Medicaid. In contrast, if this same person with disabilities lives away from the family (eg., in an institution or community home), the parents' income and resources are no longer considered at his or her disposal. Outside of out-of-home placement, the only other options available to middle income families is to pauperize themselves to become Medicaid eligible, or to forego needed medical coverage altogether.

As noted, this problem primarily affects middle income families. Many low income families can qualify for SSI or Medicaid under present deeming requirements. Likewise, high income families may be able to absorb additional medical costs without assistance from public programs. Middle income families, however, are caught in the unenviable position of having too few resources to cover medical costs without hardship but too many resources to qualify for government benefits.

To help ameliorate this crucial disincentive to family-based care, the federal government initiated a temporary review board in 1981 to consider specific cases. This board was established after President Reagan granted a special waiver of federal Supplemental Security Income (SSI) regulations in the case of a three year old child with severe disabilities named Katie Beckett. Following this special waiver, the Secretary of the US Department of Health and Human Services established a review board to consider applications from state Medicaid agencies on behalf of persons who could be serv[illegible] appropriately in the home, but due to existing eligibility criteria were found ineligible for Medicaid services. This board operated until December 31, 1984. During its tenure, 200 cases were submitted for consideration with about 150 cases approved (estimates provided the National Association of State Mental Retardation Program Directors by a member of the review board). In addition, the board's authority was extended to allow it to decide on 40 remaining applications. Of those cases submitted, most were initiated by the same six states, with about 25 states making use of the board altogether.

At present, individual states may pursue any of three options for negating disincentives to family-based care growing out of Medicaid policy. These option are: the community-based waiver program, the model waiver program, and the tax equity and fiscal responsibility act.

- The Community-Based Waiver Program (Public Law 97-35; Section 2176). This program was approved by Congress in 1981 and initiated through the Health Care Finance Administration (HCFA) to promote establishment of community based services. It is not considered a means for expanding services, but is intended to allow states a way to redirect institutional supports to the community. Though terms vary by state, the waiver program permits the provision of services that encourage family care. Examples include: case management, parent training, early intervention, respite care, personal care, homemakers, and adult day habilitation. At present, 27 states have been granted waivers and 21% of these states have stiupulated plans for using waiver dollars to fund family support services (Gardner, 1984).

  Moreover, as part of their Medicaid Waiver application, states can propose to apply deeming rules applicable to persons living in institutions to potential recipients of Medicaid-financed waiver services who are living with a legally responsible relative. To date, 20 states have elected to apply institutional deeming criteria on behalf of persons living at home with relatives.

- The Model Waiver Program. States may also request approval of a model waiver program for persons who would be eligible for SSI and Medicaid benefits if they were living in an institution or hospital but are ineligible for Medicaid assistance while living at home. This program is limited to 50 or fewer recipients per state. At present, nine states operate model waiver programs.

- The Tax Equity and Fiscal Reponsibility Act (TEFRA) (Section 134). Beginning in October 1982 states could apply to provide SSI and Medicaid coverage to persons under 18 years old who would be eligible for such services, if they were living in a medical institution. At present, eight states and one US territory offer such coverage.

Figure 1 displays the uses of the options among the 50 states. As shown, 33 states make use of at least one option, while five make use of two. Seventeen states have not made provisions for utilizing any of these three options for expanding Medicaid coverage to persons living at home or in alternatives to the institution.

By initiating mechanisms for waiving eligibility criteria, some state officials have greatly enhanced the caregiving capacity of

Figure 1: Three Options for Countering Medicaid Income Eligibility Criteria and Utilization Pattern by State

STATE	COMMUNITY BASED WAIVER (PL 97-35) DEEMING CRITERIA WAIVED	TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1982	MODEL WAIVER PROGRAM	STATE	COMMUNITY BASED WAIVER (PL 97-35) DEEMING CRITERIA WAIVED	TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1982	MODEL WAIVER PROGRAM
Alabama				Montana	X		
Alaska				Nebraska		X	
Arizona				Nevada		X	
Arkansas				New Hampshire	X		X
California				New Jersey	X		
Colorado				New Mexico	X		
Connecticut			X	New York			
Delaware	X			North Carolina	X		X
Florida	X			North Dakota	X		
Georgia		X	X	Ohio			X
Hawaii				Oklahoma			
Idaho		X	X	Oregon	X		
Illinois				Pennsylvania	X		
Indiana				Rhode Island	X	X	
Iowa			X	South Carolina	X		
Kansas				South Dakota	X		
Kentucky				Tennessee	X		
Louisiana	X			Texas			
Maine		X		Utah			
Maryland				Vermont			
Massachusetts	X			Virginia	X		
Michigan			X	Washington	X		
Minnesota	X			West Virginia	X		
Mississippi			X	Wisconsin		X	
Missouri				Wyoming		X	

families, extended the range of available services families could be offered, and contributed to the growing resolve to promote national policy that favors family care.

A review of Figure 1, however, suggests that the use of these means for waiving eligibility criteria for deserving families has been uneven. As a result, many families are left without a satisfactory strategy for coping with extraordinary medical costs because of geographic inequities.

At present, there is no consensus regarding the best means for resolving the institutional bias in Medicaid policy. Some argue that greater use should be made of existing mechanisms, especially the community-based waiver program. Several analysts, however, warn that available mechanisms are cumbersome and difficult to put into practice. For instance, Gardner (1984) reports that some states have encountered difficulties in applying community-based Medicaid waiver regulations, accounting for costs, reaching interagency agreements, designing acceptable computerized information systems, reporting expenses, and getting reimbursed. Moreover, others have observed that, perhaps in reaction to growing fears that the waiver program will actually increase aggregate costs of community services, the Health Care Finance Administration (HCFA) is making it increasingly difficult to initiate or expand waiver programs to cover non-institutionalized "at risk" populations.

In contrast, others argue that a total reconceptualization of Medicaid policy is required. The Community and Family Living Act Amendments of 1985 (Senate Bill 873) has been advanced to bring about reform. These amendments would gradually shift the federal share of Medicaid funds from institutional to community settings.

While the bill would not necessarily close all institutions, it would encourage states to emphasize community living by making available a variety of services such as habilitative programs, personal aides or attendants, medical care and family support services. Though Congress has not as yet passed S. 873, its proponents continue to press for its adoption in some form.

Private Insurance Plans

Many believe that comprehensive private insurance plans for families who have members with disabilities could obviate the necessity of public funding. At present, however, this approach is considered unrealistic by some analysts since many persons with disabilities do not qualify for private or group medical plans (Davis, 1983). Meiners (1982) notes that private coverage often is unavailable for a variety of reasons including: 1) insufficient family income for covering the costs of premiums, 2) the ongoing availability of public long-term residential options that diminish the pressure for establishing private insurance, and 3) a variety of traditional insurance concerns such as administrative diseconomies, premium pricing difficulties, and fear of incurring an open-ended liability.

There is, however, a growing recognition among private insurers that the cost of home health care is far cheaper than the cost of hospital care. Figure 2 shows the estimated savings from health care provided in the home in relation to four disability categories. Due in great part to findings such as these, many private insurers and hospitals have made home health care a crucial element of their cost containment strategies. Moreover, at least 17 states have mandated the inclusion of home care in private health insurance programs.

Such care can include case management, physical or speech therapy, nutrition counseling, medical equipment, home barrier removal, and visiting nurses.

Figure 2: The Savings from Health Care at Home

Disability Type	Acute Care Cost per month in hospital	Alternate Care Cost Per Month at home	Savings per month
Baby born with breathing and feeding problems	$60,970	$20,209	$40,761
Spinal Cord Injury with quadraplegia	$23,862	$13,931	$9,931
Neurological disorder with respiratory problems	$17,783	$196*	$17,587
Severe cerebral palsy with uncontrolled seizures	$8,425	$4,867**	$3,558

* After initial costs of equipment
** In extended care unit of hospital

Source: Aetna Life and Casualty Company; In Business Week, 1984

At present, this movement has focused on persons suffering catastrophic illnesses or injury and others with chronic health needs. Numerous initiatives, however, are testing the feasibility of providing home health care in a variety of other situations. For instance, Prudential Insurance is examining the effects of an early maternity discharge program where low-risk mothers return home within 12-24 hours of childbirth and receive postnatal care in familiar surroundings (Business Week, May 28, 1984).

Certainly, this concept should be considered in relation to accommodating the health needs of persons with developmental disabilities. Because home health care is far cheaper than hospital or institutional care, the cost of insurance coverage for such care may well be within the range of many parents. In addition, Meiners (1982) argues that if marginal adjustments were made to the existing private insurance system, the feasibility of having private insurers underwrite home health care for persons with disabilities would be enhanced. Examples of some of the changes that could be made include: 1) offering families who have members with disabilities an opportunity to share the cost of insurance with other families in similar circumstances (i.e., a group plan for the person with disabilities), 2) using the tax system to provide caregiving families with refundable tax credits with which they can purchase available insurance, and 3) using the tax system to provide employers with tax subsidies to defray any additional costs associated with including family members with developmental disabilities on existing group plans.

Coordinating Public and Private Sector Efforts

The present health care system does not actively encourage family-based care. Given extraordinary medical costs, families who cannot obtain coverage through a private insurance company realistically are presented with five options:

- Families can acquire needed funds by borrowing money or selling off assets. These approaches further reduce the family's financial resources.
- Families can expend available resources until they meet the income eligibility requirements of Medicaid and become eligible for Medicaid benefits.
- Families can acquire financial or direct medical assistance from a variety of charitable foundations such as the March of Dimes, Easter Seals and the Shriners. Unfortunately, this option does not reach all of those in need.
- Families can elect not to pay for incurred expenses. Indeed, this option is often used by families who then run the risk of being sued. It has been suggested that many hospitals no longer seriously expect some families to pay. In effect, hospitals pass on these costs to other clients who can pay for

services. Thus, to some extent an informal insurance scheme for persons with disabilities and their families may be emerging.

- Families can seek an out-of-home placement for its member with disabilities. In this way, families can avoid incurring significant medical expenses while also assuring that their member with disabilities receives needed care through Medicaid.

Setting aside the potential for using charitable foundations, none of the remaining four options offer families an acceptable and predictable means of maintaining the family unit and paying for medical expenses. In essence, the current system encourages families to deplete their resources, be less than honest, or give up their relative with disabilities. Clearly, when considering family support strategies, attention must be paid to the creation of health care alternatives that favor the promotion of the family as a care giving unit over those that, in effect, penalize families for providing such care.

Review of relevant literature reveals several possible policy options including utilization of existing mechanisms for waiving Medicaid income eligibility standards, modification or reconceptualization of Medicaid policy, initiation of a publicly financed National Childhood Disability Program (Gliedman & Roth, 1980), and encouraging increased private sector involvement in the provision of adequate health insurance for persons with disabilities.

An appropriate solution to this problem may involve a coordinated system of health benefits that weaves together some -- if not all -- of these alternatives. For instance, privately sponsored insurance options could be made more accessible to families with sufficient income to pay insurance premiums. Of course, this tact would require serious discussion among all concerned parties to set eligibility standards and to coordinate the efforts of government and private insurers. Likewise, public policy makers committed to encouraging family care must make publicly financed medical assistance plans, such as Medicaid, available to all families with insufficient resources to pay for private insurance.

Employer Centered Independent Initiatives.

Current federal fiscal policy is designed to encourage businesses and industry to make capital investments that will spur increased employment and production. Some speculate that such conditions will prompt the private sector to allocate additional resources for the benefit of workers (e.g., initiating day care programs for working mothers).

Review of the evolving relationship between employers and workers lends some credence to this view. Akabas and Krauskopf (1984) note that employers can no longer count on a continuing supply of devoted workers and therefore must endeavor to make employment attractive. Most often, these considerations prompt initiation of benefits that reinforce the relationship between employment and the well-being of the worker and his or her family.

Several analysts have documented the growing number of family-oriented benefits initiated over the years including fiscal benefits such as financing health care, flexible spending accounts, pension programs and disability retirement programs, and service benefits such as child care and counseling (McKinnon, Samors & Sullivan, 1982; Weiner, 1972; Akabas and Kurzman, 1982). These findings show that "a significant occupational social welfare system [has] developed within the worksite, with families as well as employees, themselves, gaining coverage" (Akabas & Krauskopf, 1984; p.7). Moreover, they fuel interest in finding additional means for encouraging further private sector investment in its workers, especially for those with children with disabilities (Akabas, 1984).

Private business can play an expanded role in supporting families by enhancing the employment opportunities afforded parents with children with disabilities. Of course, this can only be achieved through the cooperation of all concerned parites (i.e., government, business, and families). With ample cooperation several useful activities can be pursued. Piccione (1982b) suggests that businesses could be granted some form of tax relief whereby tax-related savings could be used to support local initiatives such as job training for caregiving parents, day care, and flexible work schedules. Similarly, analysts show that employers and trade unions can work together to offer a variety of needed services such as case management, information and referral, early intervention services or day care, and making greater use of existing benefits (Balzano & Beck, 1982; Akabas & Krauskopf, 1984). In essence, Akabas & Kraukopf (1984) view employers and workers as sharing a number of reciprocal interests. Thus, to the extent that the worksite can incorporate practices that are flexible and reinforce the relationship between work and family, both workers and employers will profit.

Relevant Issues Regarding Private Sector Involvement

The emerging interest in utilizing private sector resources to support families will likely be translated into programs of great benefit to several families. Any serious discussion of the matter, however, must be tempered by several considerations: realistic estimates of private sector involvement, coordinating public and private sector resources, equity, long term program stability, and quality assurance.

Realistic Estimates of Private Sector Involvement

Underlying any argument for increased private sector involvement in family services is the belief that businesses are *capable and willing* to make such investments. To a great extent, the capability of businesses to make substantial contributions to human services is related to the performance of the national economy; if the economy begins to fail, or if the present federal deficit is not reduced, businesses will be less apt to allocate additional resources for human services (Penner, 1982).

But even if the economy were to perform well, Boggs (1984) warns that surveys of private businesses do not reveal substantial plans for contributing to human services initiatives. Further, proponents of family services must consider that they will be competing for private sector resources with numerous other deserving groups. Thus, though businesses represent a viable source of additional support, employer-sponsored programs are not a panacea for solving chronic funding shortages.

Coordinating Private and Public Sector Resources

Systematic evaluation may disclose that certain types of services are most effective when financed through the public sector. Likewise, other service types may be especially suited to the private sector. Consequently, the goal of family service proponents should be to weave both public and private sector resources into the most comprehensive and effective service network possible. Thus, business and industry could best accommodate the needs of families by finding ways to complement -- not compete with -- already existing family support services.

Equity

Significant variance exists regarding the benefits individual businesses provide to workers. As a result, it can be anticipated that any increases in private sector involvement with family services will also vary by employer. Such flexibility is desirable due to the potential for promoting programs that are responsive to the needs of individual workers. But it also promotes inequities in the distribution of services. Families with similar needs, but different employers, may receive far different amounts and types of support. Thus, special attention must be paid to finding means for eliminating such inequities. Perhaps, businesses can pool their resources to serve greater numbers of families. Likewise, government might track all the services families receive to assure that public resources are channeled to families with the greatest service needs.

Long-term Stability

How stable are services funded through the private sector? Conceivably, public sector services are designed around some consensus concerning their value to society. Once initiated, the public has some say, through elected officials, or referendum, over whether such services should be discontinued, maintained, or expanded. In contrast, services initiated through the private sector are not as responsible to public opinion. For a variety of reasons, businesses can elect to discontinue services they initiate or curtail contributions made for service provision without consultation with employees.

Quality Assurance

One of the greatest concerns in the human services field is the assurance of quality services (HSRI, 1984). Assuring quality in the public sector is already a difficult process that would likely grow more complicated by the addition of services funded through the private sector. Given a desire to assure quality across all services, formats that are equally applicable to public as well as private services should be developed. Of course, the source of authority for planning and implementing such procedures, and enforcing any resulting recommendations for program improvement remains open to discussion.

Though the above issues are significant, they should not be used to discount the potential utility of private sector resources for supporting family efforts. Insufficient attention has been paid to the potential benefits and mechanics of encouraging local businesses to help support caregiving families. By becoming involved, business can help integrate willing caregivers into the labor force and further enhance their capacity to provide care. Such participation also could help integrate business into the mainstream of community life (Piccione, 1982b). Moreover, many argue that encouraging private sector involvement with service delivery may well result in a greater variety of services for families to choose from and in services that are more responsive to individual family needs. Thus, program planners are challenged to investigate this option and develop means for integrating business into systematic family support systems.

EVALUATING FAMILY SUPPORT PROGRAMS

Family support programs present unique challenges to professionals regarding the development of evaluation mechanisms to monitor activities, measure program outcomes, and provide direction for service improvement. Ultimately, such knowledge is necessary to justify future levels of investment in family support programs. However, to date, little effort has been made to examine administrative processes and program outcomes associated with existing family support programs. The purpose of this chapter is to examine what types of evaluation are needed, to review the difficulties involved in conducting such evaluations, and to present some of the findings from the few evaluations that have been undertaken.

Types of Evaluation Needed

Though nearly 25 states operate what may be termed "extensive" family support programs, surprisingly few of these programs have been evaluated. At least two types of evaluation are possible: process and outcome. Process evaluation is generally used to improve the efficiency, responsiveness or relevancy of an existing program, especially during its early stages of development. In contrast, outcome evaluation is designed to present conclusions regarding the overall effects or worth of a program, and often includes recommendations about whether it should be retained, modified, or eliminated.

Figure 1 shows these two types of evaluation, process and outcome, in relation to the social service system and individual families. As shown, evaluation that focuses on the process of delivering services is useful on a systems level because resulting information can help make administrative practices more efficient and responsive to family needs. Examples of the types of studies that could be undertaken include examining the time and cost involved in processing applications for service, the match between services and family needs, and the distribution of resources among individual families. Likewise, on the family level process evaluation can be used to improve the design of family support services. For instance, such evaluation might involve monitoring the family environment, changes in the number of positive family interactions, gains made by parents regarding the development of specialized caregiving skills, changes in overall stress levels, or changes in the level of adaptive skills displayed by the person with a disability. This type of evaluation would document whether the family's capacity to provide care is enhanced.

Figure 1: Two Types of Evaluation in Relation to the Social Service System and Families

	Evaluation of the Service Process	Evaluation of Service Outcomes
Service System Level	System efficiency, responsiveness	System effectiveness cost savings, meeting specific administrative objectives
Family Level	Enhancing the family's capacity to provide care	Family placement decisions, skill gains, satisfaction with services

Evaluation that focuses on the outcome of services is also useful. Such evaluation can be used to determine if various system level program objectives have been met. One example of such an objective includes realizing cost savings to the state due to diminished demand for residential services. On the family level, one telling outcome pertains to the effect of services on family placement decisions. Other outcomes of interest include aggregated tabulations of skill gains made by parents and persons with disabilities, or the family's satisfaction with services.

The evaluation of family support services can take numerous directions given the complex interactions among family service needs, the resources available to program planners, the service process, and service outcomes. Figure 2 displays the multiple factors associated with each of these evaluation targets. This outline suggests some of the many areas of inquiry that evaluation of family support service might take.

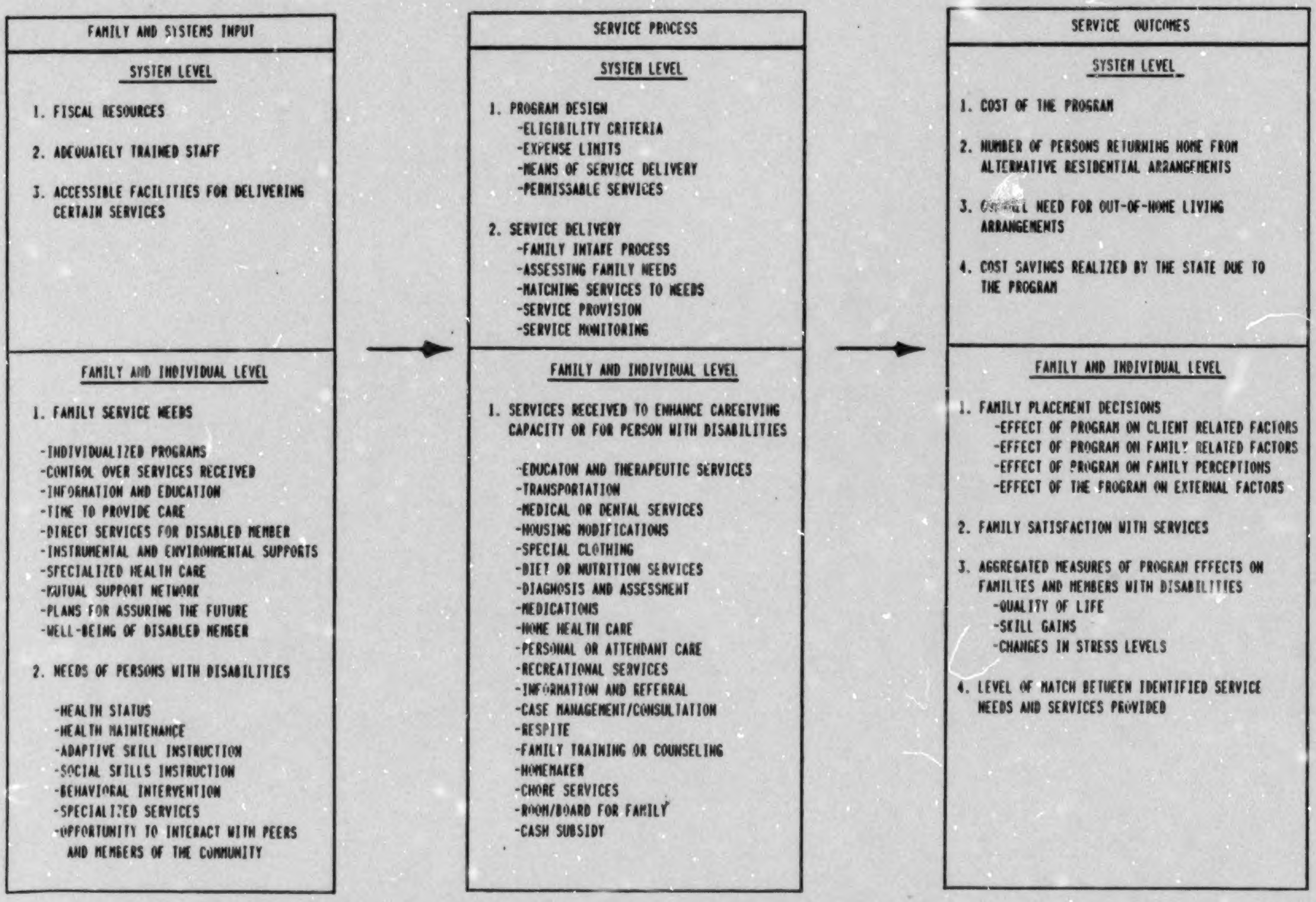
- What is the relationship between the needs of families and persons with disabilities? What client needs (e.g., daily insulin injections, special diets, reducing maladaptive behavior) can be best accommodated by meeting certain family needs (e.g., specialized information and education)? What client needs are best met by professionals outside the family home and which are best met by family members?

- How are client and family needs related to the service delivery process? Are certain administrative practices (eg., cash subsidies) more responsive to some service needs than others? What role should the private sector play in service delivery?

- What administrative practices are most time or cost efficient? Should cash subsidies utilize sliding fee schedules? How should services provided by multiple providers be monitored and coordinated?

- What types and levels of service should be made available? How can specific family needs be identified? How can the type and level of services provided to families be determined?

Figure 2: Potential Areas of Inquiry in the Evaluation of Family Support Programs



FAMILY AND SYSTEMS INPUT

SYSTEM LEVEL

1. FISCAL RESOURCES
2. ADEQUATELY TRAINED STAFF
3. ACCESSIBLE FACILITIES FOR DELIVERING CERTAIN SERVICES

FAMILY AND INDIVIDUAL LEVEL

1. FAMILY SERVICE NEEDS
   - -INDIVIDUALIZED PROGRAMS
   - -CONTROL OVER SERVICES RECEIVED
   - -INFORMATION AND EDUCATION
   - -TIME TO PROVIDE CARE
   - -DIRECT SERVICES FOR DISABLED MEMBER
   - -INSTRUMENTAL AND ENVIRONMENTAL SUPPORTS
   - -SPECIALIZED HEALTH CARE
   - -MUTUAL SUPPORT NETWORK
   - -PLANS FOR ASSURING THE FUTURE
   - -WELL-BEING OF DISABLED MEMBER
2. NEEDS OF PERSONS WITH DISABILITIES
   - -HEALTH STATUS
   - -HEALTH MAINTENANCE
   - -ADAPTIVE SKILL INSTRUCTION
   - -SOCIAL SKILLS INSTRUCTION
   - -BEHAVIORAL INTERVENTION
   - -SPECIALIZED SERVICES
   - -OPPORTUNITY TO INTERACT WITH PEERS AND MEMBERS OF THE COMMUNITY

SERVICE PROCESS

SYSTEM LEVEL

1. PROGRAM DESIGN
   - -ELIGIBILITY CRITERIA
   - -EXPENSE LIMITS
   - -MEANS OF SERVICE DELIVERY
   - -PERMISSABLE SERVICES
2. SERVICE DELIVERY
   - -FAMILY INTAKE PROCESS
   - -ASSESSING FAMILY NEEDS
   - -MATCHING SERVICES TO NEEDS
   - -SERVICE PROVISION
   - -SERVICE MONITORING

FAMILY AND INDIVIDUAL LEVEL

1. SERVICES RECEIVED TO ENHANCE CAREGIVING CAPACITY OR FOR PERSON WITH DISABILITIES
   - -EDUCATON AND THERAPEUTIC SERVICES
   - -TRANSPORTATION
   - -MEDICAL OR DENTAL SERVICES
   - -HOUSING MODIFICATIONS
   - -SPECIAL CLOTHING
   - -DIET OR NUTRITION SERVICES
   - -DIAGNOSIS AND ASSESSMENT
   - -MEDICATIONS
   - -HOME HEALTH CARE
   - -PERSONAL OR ATTENDANT CARE
   - -RECREATIONAL SERVICES
   - -INFORMATION AND REFERRAL
   - -CASE MANAGEMENT/CONSULTATION
   - -RESPITE
   - -FAMILY TRAINING OR COUNSELING
   - -HOMEMAKER
   - -CHORE SERVICES
   - -ROOM/BOARD FOR FAMILY
   - -CASH SUBSIDY

SERVICE OUTCOMES

SYSTEM LEVEL

1. COST OF THE PROGRAM
2. NUMBER OF PERSONS RETURNING HOME FROM ALTERNATIVE RESIDENTIAL ARRANGEMENTS
3. OVERALL NEED FOR OUT-OF-HOME LIVING ARRANGEMENTS
4. COST SAVINGS REALIZED BY THE STATE DUE TO THE PROGRAM

FAMILY AND INDIVIDUAL LEVEL

1. FAMILY PLACEMENT DECISIONS
   - -EFFECT OF PROGRAM ON CLIENT RELATED FACTORS
   - -EFFECT OF PROGRAM ON FAMILY RELATED FACTORS
   - -EFFECT OF PROGRAM ON FAMILY PERCEPTIONS
   - -EFFECT OF THE PROGRAM ON EXTERNAL FACTORS
2. FAMILY SATISFACTION WITH SERVICES
3. AGGREGATED MEASURES OF PROGRAM EFFECTS ON FAMILTES AND MEMBERS WITH DISABILITIES
   - -QUALITY OF LIFE
   - -SKILL GAINS
   - -CHANGES IN STRESS LEVELS
4. LEVEL OF MATCH BETWEEN IDENTIFIED SERVICE NEEDS AND SERVICES PROVIDED

- How do services affect a family's capacity to provide care? How are interactions between family members altered? How do services affect the family structure, its functions, and its lifecycles? Is the caregiving capacity of a family really enhanced?

- What are the outcomes of service delivery? Are cost savings realized by the state? Are parental placement decisions altered? Is the quality of life of individual families improved? Are families satisfied with services provided? To what extent do services satisfy the needs of families?

- What is the relationship between specific service delivery processes and program outcomes? Do certain administrative practices make a difference? Do certain services have a greater impact than others?

Of course, it will take several years to collect sufficient information to answer these and other relevant questions. However, evaluation is an evolutionary process that builds on assessment efforts over time. The intention is to develop a growing understanding of how to maximize the positive effects of family support programs.

Difficulties in Conducting Program Evaluations

Current efforts to evaluate the efficacy of family support services are plagued by two problems: 1) variation in program objectives, and 2) methodological problems.

Variation in Program Objectives

There is little disagreement that the two goals of family support services are to enhance the family's caregiving capacity and to prevent unnecessary out-of-home placement. Most would also agree that achieving these goals is in the interests of persons with developmental disabilities, their families and society. Operationalizing these goals in terms of specific program objectives, however, is another matter. There is a striking lack of consensus regarding what these programs should accomplish specifically and how program objectives should be realized. The resulting variation in program objectives and administrative practices impedes efforts to evaluate existing programs because the use of standardized outcome measures is inhibited and programs cannot be easily compared. This problem is apparent on both the system and individual family level.

On a system level, program objectives related to family support goals vary according to the availability of financial resources, political climate, and service philosophy. For instance, one possible program aspiration is to prevent unnecessary out-of-home placement. This goal in turn dictates eligibility criteria such as "at risk of being place out-of-the-home." But how should "risk" be determined? Some would suggest that to avert placement crises the notion of "risk" should be interpreted broadly and that all families with a member with a disability should be considered. Others believe that, due to restricted resources, service eligibility should be limited to families where the home placement is clearly deteriorating. Which of these eligibility options is most likely to reduce out-of-home placement? At present, there is no easy solution and this issue remains a point of contention among families, service planners, and providers.

Likewise, consider the goal of enhancing the family's caregiving capacity. Operationalizing this goal into specific program objectives is a complex and often controversial task, and requires consideration of two fundamental questions: 1) how much of the caregiving burden can the state reasonably expect families to assume? and 2) at what point does the state decide that the amount of support required by a family is unjustifiable (i.e., how much support can a family expect)? Not all service planners agree on the best means for resolving these questions. Consequently, there is substantial variance in the services families can receive around the country.

On the family level, specific program objectives are equally difficult to operationalize. This is in part due to the growing recognition that each family is unique and needs varying types and amounts of services. As a result, "programs have increasingly moved from a pre-set pattern of giving the same services to everyone, to a more individualized approach in which parents have more control over both the length and extent of their program involvement" (Weiss, 1983, p. 10). Illustrating this point are recent survey findings regarding the service utilization patterns of 101 families in five Maryland counties who participated in the first year of the state's Family Support Services Consortium (Gardner and Markowitz, 1984). Figure 3 shows the distribution of the number of families receiving various types of services at least once and suggests that families make periodic use of a variety of services.

Likewise, the amount of services provided to individual Maryland families varies. Figure 4 shows the percentage of families categorized by annualized costs of service in five counties. Though situational variables (e.g., availability of services, differing administrative practices) may explain some of the variance, these findings suggest that some attempt was made to allocate resources according to varying levels of need.

The current trend to establish programs can accommodate unique family situations is encouraging. The resulting variance in the services families receive, however, impedes comparison of program strategies and effects.

BEST COPY AVAILABLE

Figure 3: Distribution of the Number of Maryland Families Receiving Various Types of Service at Least Once*

Type of Service	Number of Families Receiving Each Service at Least Once
Family Counseling	90
Respite Care	30
Provision of Adaptive Equipment	15
Purchase of Medical Supplies	14
Day Care Services	13
Transportation	11
Recreation	11
Nursing Care	9
Medical Services	9
Behavior Management	6
Family Subsidy	5
Personal Care	5
Physical Therapy	4
Nutrition Care	4
Crisis Intervention	3
Hearing & Speech	3
Occupational Therapy	1
Psychiatric THerapy	1
Other	13

*Source: Gardner and Markowitz, 1984,

Figure 4: Percentage of Families Categorized by the Annualized Cost of Service Provision Expenditures by County Service Site*

SITE	<$100	$100-$399	$400-$699	$700-$999	$1000-$1499	$1500-$1999	$2000-$2500
Calvert County	41%	24%	12%	18%	—	—	5%
Eastern Shore	16%	45%	19%	10%	—	—	7%
Frederick County	13%	50%	38%	—	—	—	—
Baltimore City	13%	33%	33%	—	13%	—	7%
Montgomery County	21%	16%	5%	16%	16%	5%	21%

* Source: Gardner and Markowitz, 1984.

Methodological Problems

Evaluation of family support programs is also complicated by methodological difficulties involved in the measurement of program processes and outcomes. Examples of such problems include:

- The insensitivity of measures to program effects: Due to the nature of developmental disabilities, service benefits are not always easily or promptly observed. Consequently, Halpern (1984) suggests that current measures may underestimate program effects. Moreover, Weiss (1983) notes that intervention efforts centering on the entire family require that measures be capable of monitoring changes within family dynamics. Such measures have yet to be perfected.

- The absence of longitudinal evaluation: The lack of immediately observable program effects also suggests that evaluation models should be designed to view change over time. Longitudinal evaluation, however, is burdened by a variety of difficulties, including the attrition of participating families, keeping service packages received by families constant, and determining the proper statistical means for assessing change over time (Cronbach & Furby, 1970).

- Sampling related problems: Halpern (1984) notes a variety of sampling-related problems including small sample sizes, the difficulty in employing random assignment of families to service groupings, and variability in the characteristics of families and persons with disabilities.

- Mitigating circumstances: Evaluation efforts can be adversely affected by a variety of uncontrollable circumstances. For example, Tausig (1983) and Herman (1983) note that several states have initiated policies whereby out-of-home placement into institutional settings is actively discouraged. The obvious impact of such policies on parental placement decisions greatly complicates the process by which family support programs are evaluated.

- Inadequate causal models: Due to many of the problems noted above it is extremely difficult to employ group-based research techniques within a causal model. Consequently, the effectiveness of family support strategies remains largely untested in a quantitative sense.

  An effective alternative strategy involves use of single subject design methodology to establish cause-effect relationships. This type of design generates information at a slower rate than group designs because it utilizes few subjects per study. It is, however, especially suited to coping with research problems where there is great variance in program objectives and practices.

Review of the State-of-the-Art

To date, very few evaluations of family support programs have been undertaken. In contrast, ample effort has been exerted to study family life and to document the utility of particular training and habilitative techniques that might be employed in the family setting. Review of available literature reveals a wealth of information regarding strategies parents can use to teach or otherwise care for their child or adult with disabilities or that professionals can use to instruct parents about self advocacy, teaching, or other relevant topics. In addition, the effects of various situational factors on the family (e.g., availability of services, rural vs. urban life, family characteristics) are also under study.

Discrete findings such as these, while they provide guidance regarding what tools can be made available to families, tell little about the efficiency and effectiveness of existing statewide family support programs. The following sections provide information regarding the limited process and outcome evaluations that have been conducted at both the system and individual family level.

Evaluation of the Service Delivery Process

System level findings. The family support program in Florida has been examined in order to improve administrative practices. Problems were identified regarding the staffing of family support services and the means for reimbursing parents for the costs of certain services (Bates, 1983), and steps were taken to improve such procedures. In addition, the state decided do away with its system for measuring of parental income and resources to determine the amount of cash assistance a family could receive (i.e., sliding scale eligibility). Examination of this practice revealed that it cost the state more to collect information and allocate services according to a sliding scale than the state was saving through its use.

Similarly, the Minnesota Developmental Disabilities Council sponsored an evaluation of the state's cash subsidy program. Thirty-eight families participating in the program were asked a series of questions regarding how administrative practices could be improved. Respondents suggested that:

- the program be expanded to include adults,
- yearly rather than twice a year applications be required,
- local social and health service staff be educated about the program,
- parents be used to publicize the program,
- benefits be increased for families with extraordinary needs, and
- benefits be increased for emergency respite care and long distance medical phone calls (Minnesota Developmental Disabilities Program, 1983a).

Findings such as those above are useful in making administrative practices more efficient and services more responsive to families. However, our search of available literature yielded few examples of this type evaluation. Consequently, much more study needs to be done at the system level to improve services.

Family level findings. Present evidence suggests that family support services do enhance the family's caregiving capacity. Families receiving services report:

- Reduced overall stress levels (Moore, Hamerlynck, Barsh, Spieker & Jones, 1982);
- Increased time spent away from the demands of care giving resulting in an improved capacity to keep up with household routines, pursue hobbies and seek employment outside the home (Zimmerman, 1984; Moore et al., 1982);

- Improved skills for coping with habilitative needs (Moore et al., 1982; Minnesota Developmental Disabilities Council, 1983a);
- Increased capacity to purchase needed services (Zimmerman, 1984; Rosenau, 1983);
- An improved overall quality of life (Rosenau, 1983).

In addition, it has been shown that:

- Family members are willing students and can be taught several of the specialized competencies needed to provide habilitative care (e.g., Snell & Beckman-Brindley, 1984; Karnes & Teska, 1980);
- Parents repeatedly rate respite care as an extremely useful component of family support systems (e.g., Apolloni & Triest, 1983; Warren & Dickman, 1981; Moore et al., 1982);
- Cash subsidies are a useful means for easing the financial burdens of providing care (Zimmerman, 1984; Moore et al., 1982; Rosenau, 1983).

Though the above findings lend credence to the efficacy of family support programs, Herman (1983) warns that unrestrained optimism may be inappropriate. Her evaluation of family support services in three Michigan counties shows that service effects often diminish with time. In fact, after two years of services few statistically significant differences could be found between families receiving services and those that did not. Moreover, due to the methodological limitations noted earlier, a causal relationship between support services and outcomes is difficult to demonstrate clearly. Thus, researchers remain challenged to develop and implement evaluation models that document with greater clarity the effects of family support services on the capacity of families to provide care.

Evaluation of Service Outcomes

System level findings. There is insufficient information regarding the effects of family support services on the overall system of services. One popular claim is that family support services are cost effective because they diminish the need for funding expensive out-of-home residential arrangements by making it possible for families either to keep their member with a disability at home or have him/her return home from an out-of-home placement. Surely, as illustrated by relative costs of care in Michigan (Figure 5), family support services cost the state less than alternative residential arrangements. Michigan officials estimate that by serving one person at home instead of at a state residential facility, the state saves about $47,000 annually.

Figure 5: Daily Costs of Care in Various Residential Settings in Michigan*

Residential Setting	Cost Per Day
Institution for persons with developmental disabilities	$136.90
AIS/MR Residential Care	67.45
Intensive Foster Care	61.70
Group Foster Care	50.06
Family Foster Care	23.05
Family Support Subsidy	7.41

---

* Source: Stabenow, 1983

Though the accuracy of this type information cannot be disputed, it must be weighed against two other findings. First, the overwelming majority of families do not place their sons or daughters with disabilities out of the home. Thus, unless family services are successfully targeted only to families likely to seek an out-of-home placement, the cost savings realized by states would not be substantial. In fact, in the short term at least, the costs of funding an extensive family support program may even add to the aggregate costs of services for persons with developmental disabilities. Second, review of existing services reveals that once a person with disabilities is placed out of the family home, few families bring the person back home once services become available. Thus, the cost savings to states in this regard may also not be substantial.

There may, however, be long term cost savings. Persons with disabilities living with families who receive support services may in the long term have more adaptive skills than persons whose families do not receive support services. One could speculate that as these persons grow older and naturally part from their families, they will -- on the average -- be less expensive to serve because they may require less supervision and fewer services.

In sum, the claim that family support services will save states substantial amounts of money has not yet been documented. For some, until such savings are shown, funding extensive family support services appears politically unattractive. However, decisions regarding funding for these services should not be based simply on demonstrations of their cost savings to the state. Numerous other benefits to such programs have been demonstrated on the family level and must also be taken into consideration.

Family level findings. Two primary issues concerning the efficacy of family support programs involve their impact on the family member with disabilities and family placement decisions. Present evidence suggests that the family member with a disability does benefit as a function of family support services. For instance, Zimmerman (1984) reports that the majority of families receiving cash subsidies think that their child improved socially, physically, intellectually, and emotionally. Likewise, a comparison between children with disabilities living with families receiving support services and children living with non-participating families reveals that children living with participating families show significant increases in adaptive skills and decreases in maladaptive skills, whereas children living with non-participating families do not (Rosenau, 1983). The difficulty with this type evaluation, however, pertains to the need for time to pass before sizeable effects can be expected. Thus, snapshot studies or longitudinal studies of short duration are insufficient.

Regarding family placement decisions, available information suggests that among parents who seek out-of-home placements there is no one overriding factor that cuts across all families. Rather, there are numerous factors that vary from family to family, and change as the family member with a disability ages and as the family's composition, characteristics, resources, and perception of the problem are altered (Tausig, 1985).

Sherman and Cocozza (1984) present an extensive review of the literature on this matter and show that when families do decide to place their son or daughter with disabilities out-of-home, their decision is related to four factors:

1. Characteristics of the child with disabilities such as level of disability, IQ, and functioning level (Allen, 1972; Downey, 1965; Janicki, 1981; Shellhaas & Nihira, 1969);

2. Characteristics of the family such as family size, age of the parents, socioeconomic level, marital and family relations, and the presence of other family problems (Fotheringham, Skelton & Hoddinott, 1972; Hobbs, 1974; Culver, 1967; Shellhaas & Nihira, 1969);

3. Perception of the problem as related to the level of stress family members experience. Such stress can be chronic and stem from a variety of sources including financial burdens, difficulty with phsycial management of the child, lack of parenting skills, and strained family relationships (Wikler,

1983; Dunlap, 1976; Gleidman & Roth, 1980; Tew and Lawrence, 1973; Crnic, Friedrich & Greenberg, 1983); and

4. The availability of community services and social supports can diminish the severity of the problems experienced by families who provide long-term care to disabled members (Wikler and Hanusa, 1980; Cohen, 1979; McCubbin, Joy, Cauble, Comeau, Patterson and Needle, 1980; Davidson & Dosser, 1982; Waisbren, 1980; Wikler, 1981; Crnic et al., 1983).

These considerations suggest that measuring the impact of family support services on placement decisions is complicated by the multiple factors that may influence the decision. Further, the number of families that are likely to place a person with. Conversely, evaluation of support program effects on placement must be weighed against the recognition that all family-based care ends eventually either through death or assertion of independence by the person with disabilities. Thus, the more relevant question is whether the duration of family care is extended to the point where separation from the family is desirable and appropriate.

The newness of most family support programs also makes evaluation of their long term impact on parental placement decisions very difficult. The weight of the evidence that does exist, however, suggests that support services do deter out-of-home placements in favor of continued family-based care. Consider the findings of the following three studies:

- Rosenau (1983) describes a pilot family support project in Michigan that served 13 families for two years. This project offered families a $480 cash subsidy per month, a home trainer who entered the home for 20 hours per week to provide parent training, and case management services. Study results show that out-of-home placements were averted for 10 of the families and three disabled children were returned successfully to their natural families. In addition, results of a follow-up questionnaire indicate that if project services had not been available, eight families definitely would have sought an out-of-home placement and two other families probably would have.

- Herman (1983) describes a meta-evaluation of family support services that served 252 families for two years in three counties of Michigan. [Note that the 13 families involved in the Rosenau (1983) study are included in this evaluation.] Services varied somewhat by county and four models of family support emerged from the meta-analysis: intensified services through case management, intense in-home intervention with out-of-home respite, cash subsidy, and case management with respite care and cash assistance. Study results indicate that, for the most part, families retained their disabled member at home throughout the course of the projects but that the placement decisions of these families did not differ markedly from those of parents not participating in the projects. Further analysis, however, reveals that significant numbers of participating families would have sought out-of-home placements if not for the projects' services, and that families with past histories of repeated use of out-of-home options used these options less. Thus, family support services appear to have had some positive effect on family placement decisions.

- Zimmerman (1984) presents findings of a telephone survey of a stratified random sample of 38 families receiving financial subsidies ranging between $76 and $250 per month in Minnesota. Half the families had received the subsidy for less than two years with only four families participating in the subsidy program since its inception (4-6 years). Results indicate that, in part due to the program, 36 of the families had no present plan for seeking an out-of-home placement. Moreover, the program had helped make it possible for one family to bring home one of its members with a disability.

Findings like those presented above suggest that family support services can forestall out-of-home placement decisions. It is equally clear, however, that the utility of support services with regard to placement decisions has not been definitively demonstrated. What is needed is additional longitudinal research that examines service effects over longer periods of time. Given some level of variation regarding the duration of family-based care, related variables can be identified. With such knowledge, efforts can be made to modify services so that their positive effects on placement decisions are maximized.

In sum, it is apparent that much of the qualitative evidence that has been collected documents the efficacy of family services.

Families indicate that they appreciate such services, and are satisfied with their effects, including a reduction in levels of stress (Herman, 1983; Rosenau, 1983; Zimmerman 1984). Further, families report that they benefit most when they are provided with multiple service options (e.g., respite care, financial assistance and parent education) and least when they are offered fewer services (e.g., respite care only) (Moore et al., 1982). This suggests that no single service component is sufficient for achieving the goals of family support, but that several may be necessary.

The quantitative evidence is less conclusive. Much additional work must be done to gain a greater consensus regarding specific program objectives and to acquire sufficiently sophisticated evaluative measures and models. With these developments the effects of support services on the caregiving capacity of families and their placement decisions can be more definitively determined. Moreover, existing services can be modified so that they more effectively match the service needs of individual families.

Conclusion

Since 1980, several states have initiated support programs for families with members with developmental disabilities. Though this trend is encouraging, concerted efforts to evaluate the processes and outcomes of these programs have lagged behind. Such evaluation is desirable for two reasons. First, families who are or soon will be receiving services stand to benefit. Systematic evaluation of services could well result in improved administrative practices and an enhanced understanding of how to increase the caregiving capacity of individual families. Ultimately, such findings may be translated into favorable program outcomes.

Second, evaluation findings could be used to spur increased investment in family support programs. It must be understood that though nearly 25 states have extensive family support programs, the total budgets for these programs pale in comparison to what is spent on out-of-home residential services. Convincing state legislatures and other potential funding sources to invest in family support services will not be easy. But securing additional funds can be made easier if reliable information is available to document increasing administrative efficiency and positive program effects.

All in all, however, the biggest problem facing policy makers and program evaluators is the lack of clarity regarding the goals of family support services. Should services be justified solely on their ability to save tax dollars for the cost of out-of-home placement, or is the goal of improved quality of life for the family as a whole and the person with disabilities in particular a sufficient public good? The weight of all the discussion that has preceded this chapter suggests that the enhancement of the quality of life of the family -- though not directly related to cost savings -- does result in substantial benefits to the larger society including increased family self reliance, maxmization of family cohesiveness, and improvements in the productivity of individual family members including the person with disabilities. Though these gains are somewhat more ineffable, they should likewise be part of any systematic exploration of family support services.

FAMILY SUPPORT OPTIONS: A POLICY PERSPECTIVE

by

Robert Perlman, Ph.D.

Policy making requires making a choice of ends and means for the future. It rests on values and goals interwoven with analyses of forces that are shaping future possibilities and requirements. In this paper we consider policies that seem desirable, likely, and feasible with regard to family care of developmentally disabled people.* We take as our points of departure a value judgment and a fact. The fact is that family-based care of developmentally disabled people is a much larger part of the care system than institutional and community care combined. The judgment is that social policy ought to support the families who provide this care. Our purpose here is to examine current trends and developments that bear on this policy and to suggest a framework for family support in the next five or ten years.

Given our goal, the challenge is to achieve a reasonable balance among the programs that will:

1. Strengthen the ability of families of different types and capacities to care for a developmentally disabled person at home;
2. Maximize the quality of life for the disabled person;
3. Maximize the quality of life for the family as a whole;
4. Prevent inappropriate out-of-home placements; and
5. Develop a system of supports that is politically and economically feasible.

These objectives are not presented in any order of importance. They are, in fact, highly interdependent; each contributes to the accomplishment of the others.

---

* The assistance of Gunnar Dybwad, Professor Emeritus of the Heller School at Brandeis University, in preparing this paper is gratefully acknowledged.

We must note first that definitive evaluations have not yet demonstrated to what extent supportive programs do, in fact, contribute to the objectives set forth above. However, the weight of available evidence indicates some effectiveness in bolstering family capacity, improving the status of the developmentally disabled person, and reducing institutionalization. Nevertheless, it should be acknowledged that family-based care is not necessarily the best course for all families. Moreover, such care ought to be available primarily for developmentally disabled children and adolescents living at home. Adults should be enabled to live independently of their families and, for that reason, one of the components of family support should be preparation for separation.

As with any effort to project social processes into the future, this one is bound to deal with great uncertainties and ambiguities, as illustrated by the very first question we raise: can we anticipate changes in the number or the needs of developmentally disabled children? Advances in medical technology suggest that more babies with mental or physical impairments will survive. If so, not only the total number will increase but children who are severely disabled will survive in even larger numbers.

These potential increases could be offset by several factors. One is the outcome of the political debate over parental rights with regard to measures to sustain the life of severely disabled babies and, indeed, persons of all ages. This will be affected by the decisions of parents, informed during pregnancy of abnormalities, to opt for or against abortion. On the other hand, medical advances can prevent what hitherto have been severe handicaps (e.g., phenylketonuria) and can reduce the extent of disability and dependency.

On balance, the number of children requiring long-term care will "increase slightly in the next 10 years" according to one study (Callahan, Plough & Wisensale, 1981). Moroney (1979) foresees even more of an increase: "The prevalence of disabilities is increasing and will continue to grow at an accelerated rate over the next 25 years." We shall assume in this paper a moderate increase in the number of children who are disabled.

Factors For and Against Family-Based Care

At present the great majority of families care for their developmentally disabled children at home. In projecting what is likely to happen to this large but vulnerable family-care system in the next decade, we begin with those factors that tend to diminish the size and effectiveness of family based care. We group them under three categories: demographics, attitudes and ideological factors, and political and economic tendencies.

Demographics

One must always wonder whether today's population trends are likely to persist or are only temporary. Bearing that caution in mind, there are a number of changes now under way that seem likely in the near future to have the effect of shrinking the pool of available caretakers, most of whom have traditionally been women (U.S. Bureau of the Census, 1984).

1. The size of families is decreasing and the number and proportion of persons not living with any relatives is increasing. Non-family households rose from 19 percent of

all households in 1970 to 27 percent in 1982, reflecting both the rising age at first marriages and the higher incidence of divorce and separation. These tendencies reduce the potential availability of siblings and other relatives for a role in family care.

2. The number of one-parent families is up sharply, thus depriving the remaining parent of the other spouse's daily participation in family care. Between 1970 and 1982 the number of two-parent families dropped by four percent and one-parent families doubled.
3. The economic impact of families headed by one parent (90 percent of the time it is a woman) is tremendous, further weakening the capacity of many families with a developmentally disabled member. In 1981, for example, the median income of all married couples was $25,070, while for families maintained by women it was $10,960, at a time when the official poverty threshold was $9,287 for a family of four.
4. More and more women are entering the labor force. From 1970 to 1982 the proportion of women rose from 43 to 53 percent. Whether they are the mothers of children with developmental disabilities or are other female relatives, the effect is to diminish the care-taking pool even further.
5. The median age of the population is increasing, from 27.9 years in 1970 to 30.6 only twelve years later. Potential care-takers are older and presumably have less physical stamina for the demands of caring for a disabled family member.

6. The implications of the movement of people away from central cities is unclear. The greater accessibility of services in urban areas may be offset by greater family and neighborly involvement in the caring function in rural and suburban areas.

Attitudes and Ideology

1. As life-styles change there appears to be a greater interest in self-fulfillment and individual freedom among family members. This can militate against taking on the responsibilities of family based care.
2. On the other hand, there is a strong belief among many people that parents should be responsible for the care of their children, including those who are disabled. Some believe, moreover, that since parents for the most part are already providing care at home for disabled children, there is no need to spend public money, -- especially if there is a risk that public support might erode parents' sense of responsibility.
3. There is another current of belief on the part of some people that parents of children with developmental disabilities are somehow deficient or patholoical and, therefore, not worthy of public support.
4. As part of a general disenchantment or rejection of "the Welfare State" there is ideological and political resistance to the costs of supporting family based care and to the growth of services and bureaucracy that greater public support might entail.

Political and Economic Factors

1. Public policy and financing may continue for some time their bias in favor of institutional care. There is some evidence that even in the light of the growing system of community-based services, there is a tilt away from helping families with home care of children and toward out-of-the-home programs for adults (Morell, 1983).
2. Financial eligibility requirements for SSI and for Medicaid discourage many families from a sustained commitment to providing care.
3. The state of the economy for the next five to ten years is hard for economists to agree on. Whether Federal and State tax revenues will go up or down is unclear, as is the readiness of the voting public to support increased expenditures for programs of social support. However these factors play out, it seems a safe bet that competition for funds in the area of social programs, such as those involved in fostering care in the natural home will be stiff.

Against this formidable array of forces working against support for family based care, what factors appear on the positive side?

Factors Supporting Family Based Care

1. On a family-by-family basis, care at home is apparently less costly than either institutional care or care in community based facilities. This can be persuasive in the political arena. However, what is difficult to project is whether or not the aggregate cost will increase as a result

of a "woodwork effect." That is, will so many additional families "come out of the woodwork" and claim assistance if it is more readily available, that the total cost in tax dollars will be increased?

2. Additional research may help to document the advantages of family care for the disabled person, their families, and society. For example, studies indicate that parents can be taught specialized caretaking skills that, otherwise would be performed by highly paid professionals.
3. The continued growth of community services that serve the aged and other groups can be a positive development.
4. A Princeton University study reports that the states have "embraced and preserved" most of the social programs that Congress turned over to them in recent years. The states have "replaced more of the Federal money than had been generally expected" following the cuts made by the Reagan administration (The New York Times, June 1984). Whether policy-making in this specific area at the state level will be supportive of families remains to be seen.
5. As a result of legislation, the public schools have become a significant resource for family support.
6. The concern about the American family and the view that its sense of responsibility is being undermined can be made to work for family support as a way of saving families from going under. The facts cited above that indicate a shrinking pool of caretakers can be used to justify offering compensatory assistance to enable families to continue carrying out their caring function.

Those responsible for developing policy concerning Family based care will need more than an awareness of the factors we have been outlining. They will require much more information than is now available on the ways in which FBC currently functions and about the population involved.

Gaps in Current Knowledge

We take note here of important gaps in our understanding of where we are. There does not appear to be solid information on these elements:

a. The financial and other costs incurred by families providing care to a developmentally disabled child over and above the normal costs of rearing a non-disabled child;

b. The services that are now being supplied, in what quantities and by whom, to support families;

c. The preferences of parents as to the type of supports they want;

d. The expenditures of each level of government and the private sector for family support;

e. The effects of support services on families and disabled persons;

f. Cutting across all these questions is the simple lack of data on disabled people and their families. We are not even sure about the numbers of people involved and, for purposes of planning, we know too little about the degree of disability or dependency of the children or the income, size, and other characteristics of their families.

With all these gaps in knowledge, the need is not for sporadic and disjointed snapshots of one or another element. What is required is a set of longitudinal studies that track these elements over time in relation to each other.

With regard to item (f), the characteristics of families who are providing care at home, a crude description can be gleaned from the Survey of Income and Education conducted by the U.S. Bureau of the Census in 1976. Several questions about disability and the need for personal care were included in the survey of 181,000 families. We have identified 1,270 families in the SIE data who are caring for a mentally retarded person at home.

This information is subject to several qualifications. The respondent was asked in each family whether there was someone living at home who was mentally retarded. The designation was thus made by a family member and could well be under-reported, though it should be noted that half the respondents said the condition of retardation was diagnosed by a professional. The survey estimated that there were 866,000 persons categorized as retarded in the United States living outside of state institutions. This is lower than most other studies suggest. Second, the data refer only to mentally retarded people and not to the total developmentally disabled population, though the former constitute a high proportion of the latter. Bearing these caveats in mind, a national sample of 1270 families with a disabled member living at home is still useful in an area where so little is known.

1270 Families Engaged in Family Care

The Survey of Income and Education (SIE) asked two questions that permit an estimate of the degree to which mentally retarded persons living at home depend on others for assistance. The respondents were asked (1) does this person "need help from others in looking after personal needs, such as eating, dressing, undressing, or personal hygiene? Frequently, occasionally, rarely?" and (2) does this person "need help from others to go outdoors or to get around outside their home? Frequently, occasionally, rarely?" In analyzing these data, our focus was on the degree of dependency not on disability per se. For this purpose we grouped the 1270 individuals into three categories, which resulted in the following: (1) 26 percent were severely dependent because they frequently needed personal care; (2) 18 percent were moderately dependent because they frequently needed help outside the home or they needed either kind of help occasionally or rarely; and (3) the more independent individuals, who amounted to 56 percent, who were said by their families to require neither kind of help. These data are not too dissimilar from the 1975 determinations under SSI, where 20 percent were severely retarded; 14 percent were moderately retarded; 12 percent were mildly retarded; and for the remaining 42 percent the level of retardation was not specified since no test results were developed (Callahan et al., 1981, p. 12). The SIE information permits us to compare the families providing home care with the general U.S. population, as well as to make comparisons among care-giving families based on the degree of dependency of their retarded relative.

In the development of policy to achieve the objectives suggested at the beginning of this paper, the economic situation of families is a critical factor for several reasons. Many families must struggle with extraordinary expenses in caring for a disabled child; obviously this falls most heavily on low-income families. Second, limited income creates pressures for family members to go out to work, thereby reducing the time and energy available for the caring role. We turn first, therefore, to compare family income for the United States with the SIE sample, as shown in Table 1.

Table 1: Income of Families Giving Care and All U.S.Families, 1975-1976 (in percent)

	U.S.	SIE Sample
Income Under $10,000	33.2	45.1
$10,000 - 14,999	22.8	22.4
$15,000 - 24,999	30.4	22.2
$25,000 or more	14.1	10.3
	100.0	100.0

Sources: Author's tabulation of unpublished data, U.S. Department of Commerce. Bureau of the Census, Survey of Income and Education, 1976, and Statistical Abstract of the United States, 1981, Table 725, Family Income for 1975.

It is clear that families caring for a retarded person at home had, on the whole, lower incomes than the general population. The data show that 45 percent of the SIE families had incomes under $10,000 in contrast to 33 percent of all families. Conversely, 45 percent of all families had incomes over $15,000, while only 33 percent of the SIE families exceeded that income level.

This comparison is even more stark when one considers that in 1975 only 9.1 percent of all U.S. families were living below the official poverty level, while 17.3 percent of the care-giving families were poor by this definition.

In 1976 one-fourth (24.2 percent) of all U.S. families were headed by women. The same proportion (24.2 percent) of the SIE sample were female-headed families. As we pointed out earlier, this means very limited income for a substantial number of families with disabled members and only one parent to assume the day-to-day responsibilities. Approximately 12 percent of all families were in minority groups as compared with 16 percent in the sample.

Balanced against the lower incomes of care-giving families is the finding that they are slightly larger than families in the general population, presumably giving them a larger reserve of care-takers on which to draw.

Comparing families within the sample in terms of the three levels of dependency, there are indications that the Independent group is somewhat more disadvantaged than the Severely Dependent and the Moderately Dependent groups. The differences are not large except for the fact that almost twice as many families in the "Independent" group are living in poverty (20.4 percent) than in the "Severe Retardation" group (11.5 percent).

A slightly higher proportion of families with "Independent" disabled relatives are female-headed and have fewer than four people in the family when compared with the other two groups. As might be expected, more families of Severely Retarded people (32.1 percent) are receiving SSI than the other two groups (26 - 29 percent). The three groups receive benefits from Aid for Dependent Children (AFDC), Veteran's Administration (VA), and other public sources in approximately the same proportions.

In short, the care-giving families in the SIE sample are less well positioned economically than the general population, though they face greater demands on their financial resources. A higher proportion of these families have only one parent in the home.

The SIE data are limited in several respects and certainly there is a need for follow-up studies to determine trends since 1976. But these two findings -- concerning income and female-headed households -- strengthen the case that care-giving families face greater obstacles and burdens in maintaining a mentally retarded member at home than "the average American family" would if it were in the same situation. For the many, many families who want to provide care, despite their disadvantages, the argument for support from the rest of society seems strong and in keeping with concerns for the viability of American families.

As we look ahead into the near-term future, our projections of public support for these families need not be based entirely on speculation. Using the old saw that the best predictor of future behavior is past behavior, we can get some idea of the directions that are likely and possible by looking at what is now being done at the state level.

The very fact that at least 22 states have taken some action in the past decade to develop programs of family support (and several others are considering new programs) demonstrates the political feasibility of moving toward the goal enunciated at the outset. The information on these programs (See Part II; Chapter 3), provides a preliminary picture of state activity in this field. These data are subject to several qualifications. It is not clear how much of what was reported by respondents was "what is on the books" as distinct from what is in operation. Nearly all states in their survey reported some program in existence, though less than 25 can be said to be extensive. In any case, the available information indicates what the states aspire to achieve.

Fifteen of the 22 states reviewed in depth provide cash subsidies to families (of these 15, seven also offer inkind support services). In a majority of the states the subsidies range between $200 and $300 per month. Three states specify no dollar limit but are restricted by limited program budgets. Of course, one does not know how many families each state would be able or willing to subsidize, since the programs are young and only six serve more than 150 clients.

Cash subsidies clearly give families more control over the kind of assistance they will receive than services in-kind. It is important, in the light of the principle of empowerment of families, to note that seven of the 22 states reviewed furnish families only with services and no cash grants.

The eligibility criteria imposed in the 22 state programs describe the target population and, by implication, the objectives of each state program. The criteria can be arranged according to diagnosis, age, living arrangements and income. The first observation to be made is that no clear, predominant patterns emerge. The information below is limited to what appears in Tables 2, 3 and 4 of the national survey results reported earlier (Part II; Chapter 3).

Diagnosis. The requirement is quite general in most states. Twelve states refer to developmental disabilities, seven make specific reference to mental retardation, three simply specify "disability," two specify a variety of disabilities (e.g., autism...), and one program refers to children returning from an institution. Four states address their efforts specifically to severely disabled persons

Age. Sixteen states set no age requirement. Three refer to children, two to persons under 18, and three to persons under 22.

Living arrangements: Most states gear their programs to people living with their families. Three states consider eligible those presently living in a state facility but who will return home. Six programs give priority to persons "at risk of out-of-home placement."

Income: Fourteen states do not specify income limits; eight are geared to lower-income families or those who cannot bear the costs of care.

Overall, disabilities are not tightly defined as a basis for being eligible for these state programs; only four of them are limited to the most severely disabled. Only five of the programs specifically say that they are addressed to children (under 18 years of age). Only eight target families with insufficient resources. Three programs are aimed at disabled people living away from home.

Some notion of the relative emphasis given by the states to different types of services can be obtained from a review of permissible services. Table 2 displays those services available in the 22 states.

It should be noted that one important need is not addressed in these state programs and it concerns provisions for care of the disabled child after the death or incapacity of the parents or other relatives. This is a major source of concern to parents. In an earlier chapter, data from a national survey are presented that describe 11 programs that provide future planning services (See Part III; Chapter 2). They are quite new programs and their efficacy is not yet clear, but the argument is made that they should be integrated into family support systems.

The listing of services in the state programs is not so innocent as it seems, for the way in which services are labeled and classified says a good deal about the intent and the content of the programs (and probably about the goals of the classifier as well). Clarity on this issue is important as we turn now to a discussion of possible directions for policy to support families.

Table 2: Service Type by the Number of States Providing Each Service

No. of states	Type of service
	Equipment/Environment
20	adaptive equipment
10	clothing
14	home renovation
	Health Related
14	medical/dental
10	diets
7	home health care
17	therapeutic
8	medications
	Personal Care
16	transportation
21	respite
5	attendants
2	room and board
	Counseling
15	counseling
9	diagnosis/evaluation
2	information/referral
	Home Help
3	chore
7	homemaker/housekeeper
	Education
15	parent education
	Recreation
5	recreation

Possible Directions for Family Care Policy

The following discussion of future policy is divided into four parts. First, we return to the objectives set at the outset and raise the thorny question of priorities among them, using models of family support that emphasize one or another objective. Second, we take up some issues of equity affecting sub-populations among families providing care. Third, we look at mechanisms for delivering programs, and, fourth, we touch on the matter of finances. The paper concludes with a suggested framework for a future program of family support.

Using Theoretical/Programmatic Models

At the beginning of this paper we said that the objectives of family based care should be: to strenthen the capacity of care-giving families, to maximize the quality of life for the developmentally disabled person and/or the family; and to prevent inappropriate out-of-home placements -- all within a system that is economically and politically feasible.

But whose needs rank first. . .second. . .third? Those of the disabled individual. . .the family. . .society? Should priority be given to services that parents want most or to those that appear to have the greatest impact on costs to the public? Or should we give highest place to services that make the greatest difference in the life of the disabled person?

Only by trying (with no guarantee of success) to sort out these questions can we establish criteria for determining which services are crucial and which are peripheral. It may help in this search if we have before us a number of models or points of emphasis, which we can examine in the light of the demographic and political trends noted earlier. We offer these models with the caveat that they are over-stated for the purpose of discussion. They are certainly not mutually exclusive.

The economic model. Services can be provided or paid for so as to encourage parents to go out to work and to increase their earnings. This was the motivation behind the original tax deductions for home care, as it was for child care (Perlman, 1983); more will be said later about the use of the tax system for this purpose. This approach has much in common in its aim with work training for welfare recipients in that both focus on self-support and converting tax-consumers into tax contributors.

Given present political trends, one advantage of this model is that it appeals to those who want to reduce public expenditures and those who want to re-enforce the resonsibilities of families. Further, it does assist those parents who want to get out and work. At the same time, it has the potential of creating disadvantages for parents who prefer to devote their time to home-based care.

The Quality of Life Model. Here the priority is on programs that will improve the social, psychological, and physical well-being of the disabled individual and/or the family. This may, on first glance, appear to run against the trend to cut costs and shrink the size of service establishments. However, assuming that it is carefully evaluated, it may in the long run turn out to be cost-effective if it helps to prevent or delay out-of-home placements. How these dynamics work is illustrated by recreational services.

Recreation was cited by service providers as needed but in short supply (Lakin, et al., 1982). It will be recalled that recreation came out near the bottom of the list of services provided by the new state programs. Yet, as Gunnar Dybwad persuasively argues, recreational services -- especially those involving a disabled child in physical and, therefore, social contact with other children -- contribute not only to quality of life, but to the disabled child's development and ultimately to the outcome of family based care.

The Medical Model. Much criticism has been hurled at those who view developmental disabilities as diseases to be cured and who build service programs on that basis. The critics charge that this perspective is myopic and self-defeating. However, there seems to be little doubt that medical and other health-related services are crucial to families engaged in home care. These services become a terrible drain on finances when families must pay for them out-of-pocket. Hence, some provision for health services as one element in a "floor of support" for care-giving families must be made.

The "Daily Grind" Model. Much of the literature hammers home the point that, perhaps even more than financial aid, parents want help with the practical, daily demands of living when they are carrying the responsibilities of home care. Assistance with meals, shopping, bathing, house cleaning, transportation and the like is critical for many families, especially those whose children are severely disabled. To what extent this goal can be met through community services, such as those addressed primarily to the frail elderly, remains to be seen. The degree to which practical help of this kind can be obtained through volunteers, other relatives, or by exchange with other care-giving families should be tested by agencies concerned with family support. Perhaps, using family care models for the frail elderly as a model will be useful.

The Self-Help Model vs. The Professional Model. These are posed as alternative approaches. Proponents of parent empowerment seek to give major responsibility for decisions to parents. Others insist on the expertise of professionals in both decision-making and implementation, on the assumption that physicians, social workers, nurses, and others have the training and experience to assess, plan, and deliver services with an effectiveness that non-professionals lack. The rationale for the self-help emphasis rests in part on giving parents a greater stake in a process which they will largely control and one which respects their dignity and rights. This can be enhanced through mutual support groups that professionals cannot easily tap, and other resources, such as churches and neighborhood organizations.

The limits and the failures of professionalism are now more openly recognized (Morris, 1983). But there are also limits to the emotional and physical resources of parents and their expertise. The center of gravity, as is so often the case, may lie between the two extremes. Neither professionals nor parents can or should bear the exclusive responsibility. An ideal program would treat them as partners not as a hierarchy.

Home Care vs. Community-Based Service. This has also been presented as a dichotomy. Morell (1979) argues that funding patterns favor out-of-the-home programs for retarded adults and short-change children in their own homes. On the other hand, Lakin (1982) believes that the same program resources are needed to support families as well as community-based residences. It seems ironic, in a country as richly endowed as this, to pit two such programs against each other. In relative terms, however, it can be argued that family support has been under-funded and will in the future require considerably more resources than it has hitherto been accorded.

The Service Model vs. The Cash Model. Boggs (1979) cautions against putting too much emphasis on cashing out benefits "unless dollars can be translated into something else perceived as critical." She cites studies to the effect that the cost of home care is not the main problem for families; the biggest problem is "the amount of care and supervision" they are required to give. Some of their sense of strain has to do with the single issue of time, time to do what is necessary for the family as a whole and for the disabled child. In part, this can be alleviated by having someone on hand to share the responsibilities on a daily or weekly basis, as is true with difficult tasks such as lifting and bathing some children.

To a considerble extent cash and services are interchangeable. In the example mentioned above, a homemaker could be sent in or the family could use some of a cash subsidy to hire someone to take part of the burden. But not all services can be easily purchased and some would be financially beyond the reach of most families, hence the preference of many for a mix of services and cash.

Obviously, none of these models is valid as a sole guide for policy, but each contributes considerations and cautions that must be taken into account. Disabled individuals, their families, and the community at large all have legitimate claims on the resources that must go into supporting families. Policy-makers will have the difficult job of balancing these claims and making trade-offs that are both humane and reasonable. For example, there is no answer to the question of whose interests should prevail when clear-cut choices have to be made between the welfare of the disabled child and the welfare of the rest of the family. No answer is possible because the question is flawed. Improving the quality of life for the disabled individual contributes to the quality of life for the family as a whole; certainly the reverse is true. No part of this system can be utterly neglected, but neither can it become superordinate in shaping policy and programs.

Issues Regarding Equity

Before attempting to apply these models selectively, we ought to consider another set of options that stem from the issue of equity among potential recipients of support. We refer here to sub-populations of families distinguished in terms of (a) income; (b) the degree of dependency of the disabled child; and (c) the type of area in which the family lives.

Income. It was clear from Table 1 that we are dealing here with families who have on the whole lower incomes than the general population. Some 45 percent of the families in that sample had incomes below $10,000 in 1976, compared with 33 percent of all U.S. families.

This fact must be borne constantly in mind in devising family support programs for the future. For example, it was stated earlier that planning for the care of a developmentally disabled person after the death or incapacity of the parents and other relatives is a serious concern. Various insurance plans, estate planning, and the like are developing to deal with this concern. But it is clear that any such scheme that relies solely on the resources of the families will be extremely inequitable in the face of the low incomes of many care-giving families who cannot participate in such financial planning programs.

Some care-giving families are qualified for assistance under Medicaid and SSI. On the other hand, families slightly above the income limits set for these programs often are not eligible for services without paying, thereby creating a serious inequity. The same is probably the case in some of the state programs.

Future programs should redress this inequity by making some benefits accessible without cost to all families involved in family based care. At the upper end of the income scale, it seems justifiable to expect more affluent families to bear a larger share of the cost of public services for family based care. In all instances we would opt for counting cash subsidies and other services as benefits and not as taxable income. Above all, the incredible anomaly in establishing eligibility for public support, that is, counting the income of parents when the child is at home but not when the child is institutionalized, should be corrected since the present situation creates great inequities.

Extent of Dependency and Disability. What is the proper allocation of resources among different levels of disability? Moroney (1979) has pointed to the competition for resources between the families of severely retarded and moderately retarded children. Clearly, the former need more assistance and resources than the latter. But there is a minimum amount of support that should go to all families not only as a sign of society's recognition of their situation, but as a preventive measure to minimize strains in even those families with the least disabled children. Our analysis of the SIE data suggested that the families of "Independent" persons were, in fact, in poorer circumstances than the families of the Severely Dependent children.

Geographic Areas. The distribution of services between rural, suburban, and urban areas and the implications for family based care are not well documented or understood. But certainly there can be no reasonable equity if some families are isolated in places where the lack of services and transportation deprive them of support.

Mechanisms for Determining Benefits

Cutting across these issues of priority and equity are programmatic questions that must be confronted in planning for the future. One of the most important of these is the question of how the package of services and/or cash is to be determined for each family.

A standard entitlement to a set of benefits for all families would fail to give adequate recognition to levels of dependency, income, and other significant differences. But unless there is some minimum entitlement, many families could be completely bypassed in a system constructed entirely on the basis of "the extent of need for assistance."

Case-by-case determination offers the advantage of tailoring benefits to differences among families and differences over time in the same family, but it harbors serious disadvantages. It can lead to greater bureaucracy and greater cost. Moreover, as we have already noted in connection with the "professional model," there have been widespread criticisms of the ability of professionals to make and implement decisions of this type, particularly when the families affected have little or no voice in the process.

A compromise between these two approaches, which carries some of the advantages and disadvantages of each, is the distribution of differential benefits according to categories that reflect the degree of dependency of the disabled person, the family's income, and perhaps other criteria. Such a system does recognize differences among families, but guarantees some assistance to all families providing care, at the same time that it restrains the size of the service establishment and presumably the cost.

Another program device that requires consideration for the future is the mechanism for dividing responsibility between the family and the community. One arrangement is for the community to furnish a certain amount of services and/or cash to all families, with the families expected to supply whatever is needed beyond that amount. The inequities that would ensue, however, in terms of levels of need, are too obvious to require comment.

The reverse strategy is also possible. Each family could be required to provide some basic amount of care, perhaps measured in time units, with community agencies supplementing in cash or services what is needed beyond the family's input. This device acknowledges that ideological position that expects families to shoulder their responsibilities for their children. It could, however, create a situation in which more affluent families could buy themselves out of the responsibility by employing outside help, while lower income families would have to invest their energies and time in direct care-giving activities.

Under most arrangements for shared responsibility, questions of accountability, control, and decision-making arise. Should a service plan be negotiated case-by-case, thus setting the framework for payments or service delivery? Or, within some limits, should the family determine its needs, obtain the services it wants, and then be reimbursed for its expenditures? Either system must be flexible enough to permit adjustments, eepecially at critical junctures when families are over-burdened and most apt to consider out-of-home placements.

Should we be concerned about run-away costs if families, either on their own or in concert with professionals, determine service plans? The question deserves study, but we do have preliminary evidence from a researcher working in a parallel field, long-term care of the disabled elderly. Sager (1983) found in an experimental program that "all three groups -- patients, families, and professionals -seem to recommend care in reasonable and equitable ways" and he concluded that "fears of uncontrollable spending ensuing from patient or family influence over care planning find no support in the present study."

Where Are the Dollars and How Do You Get at Them?

As John Noble observed,

> "...the single most important threat to the welfare of mentally disabled people at this time is how public financing issues are resolved. We all know that family and professional judgments as well as political decisions at every level of government are influenced by considerations of who must bear the costs of care and treatment for handicapped persons... People will have their needs defined in relation to where the dollars lie." (Noble, 1981)

The conditions under which Federal funds are made available to states; state funds to localities; funds from any source to not-for-profit and proprietary agencies; and ultimately the requirements that families must conform to in order to obtain assistance -- all these mechanisms become the forces that drive the "family-based care system" and these interlocking incentives and disincentives must be taken into account.

It is beyond the scope of this paper to go into these complexities in any detail, but a few general comments are in order. The efforts of about 22 states to date to mount extensive programs of family support are encouraging signs of forward movement. But the very limited and tentative nature of those programs -- both in terms of assistance and coverage of families -- argues for an underpinning of nation-wide financial support from the federal government.

As we pointed out earlier, there is a concern about the "woodwork effect" of broadening programs of family support. But this calls for a closer look, since there are two kinds of outcomes under this rubric. If utilization of services and cash subsidies skyrocket, thereby vastly increasing public expenditures (wherever they come from), it may indeed mean that there is some over-use and inappropriate use of the program by those people who do not conform to the eliibility criteria. This is a legitimate concern and one that will require prudent and reasonable measures to restrain improper exploitation of public funds.

However, there is another kind of "woodwork effect" that ought to be welcome, despite the fact that it will increase costs. Many families now struggle to maintain a developmentally disabled person at home with little or no outside help. Some are able to sustain this for longer or shorter periods of time; some understandably collapse under the weight and the human consequences for all concerned are serious and, in financial terms, costly. If families such as these come forward to make claims on an expanded program of family support, we must reconize both the legitimacy and the desirability of expenditures on their behalf. In this connection, it should be recalled that Sager (1983), cited above, found no evidence that there would be run-way costs if families were given more control over service plans for the long-term care of the disabled elderly.

Conclusion

This paper has surveyed demographic and political trends and policy issues that ought to be taken into account in planning family support prorams for the future. Before suggesting the outlines of such a program, it may be useful to summarize the trends we have described and to indicate their implications for policy planning, as shown in Table 3.

Before projecting these guidelines into a program outline, we ought to explain why one element is not included, namely, the use of the tax system to support care-giving families. We believe that a system of incentives to families to undertake and continue home-based care is a more promising strategy than one based on compulsion or negative consequences for families unable or un-willing to do so. But we do not look on the tax system as a means of accomplishing this.

The attempt to use tax deductions and later tax credits to encourage families to care for a disabled relative has, over 30 years, reached only a very small proportion of eligible families (Perlman 1983). Second, the average expenses claimed range from $700 to $1,400 and probably fall short of the actual expenditures many families incur. But most importantly, the tax device favors high income families, since it is closely tied to full-time employment, and effectively excludes poor families from its advantages.

Proceeding, then, with the guidelines set forth in Table 3, the elements of a comprehensive program to support families caring for a developmentally disabled child would include these five elements:

Table 3: Demographic and Political Considerations and their Political Implications

1. Low income status of many families caring for disabled members	Benefits must be accessible to all income levels and must be seen to be fair
2. Differences in degree of disability	Programs must provide assistance in relation to disability but must also serve the least disabled, and be flexible as conditions change.
3. Shrinking pool of caregivers (more female-headed families,etc.)	Assistance should be scaled to size and composition of families
4. Disabled children outliving parents.	Build in care and security for disabled children when parents are unable to provide it.
5. Rising costs of medical and other health services	Assurance that these extraordinary expenses for care will be covered.
6. Concern that parental responsibilities not be eroded.	Programs should supplement not replace family effort, but also recognize parents' rights in decision-making.
7. Growth in state financing and community-based programs for the elderly and others.	Tap into these for family support, and utilize states for administration
8. Increasing questions about the Welfare State.	Programs should restrain growth of unnecessary bureaucracy and balance self-help against over-professionalism.
9. Resistance to rising costs of social programs.	Build accountability and reasonable controls into family support programs

1. Coverage of medical and hospital expenditures on behalf of the disabled child for all families, reduced proportionately for families above a specified income level.
2. A standard allowance (perhaps $100 per month) for all families for supports the family deems necessary, such as respite care, homemaker services, and so forth. This would apply regardless of the degree of disability.
3. For persons determined to be substantially or severely disabled, a supplementary budget (with an upper limit of about $200 per month), keyed to family income, would be available. This would be determined jointly by the family and a case consultant. Provision would be made for a one-time, start-up grant for such expenses as home renovation, special equipment, etc. It is estimated that approximately one-fourth of the developmentally disabled population living at home would receive these benefits.
4. Case consultation and advocacy services to be provided without cost to all families, to work out an overall service plan and to link families with self-help groups and community resources.
5. A compulsory and contributory social insurance program to which parents would contribute in accordance with their income, which would provide funds for out-of-home placement for young adults and/or for the continution of services at the level supplied to the disabled person before the death or incapacity of the legal caretaker.

The suggestion is that medical and hospital coverage, the standard monthly allowance, and the disabled survivors' insurance scheme be financed by federal funds, but that only the survivor's insurance be federally administered. The supplementary budget program and case consultation would be state-financed and the latter administered locally. Thus, except for survivors' insurance and case consultation, the program would be state-administered. This proposal assumes the continued phasing out of state institutions and the shifting of funds to family support and community-based care.

This proposal is advanced here not as a blue-print for a new program, but as a means of articulating the policy considerations that have been developed in this paper and, hopefully, as a stimulus to discussion, disagreement, and better planning to support the families about whom we are concerned.

PART IV: RECOMMENDATIONS

Chapter 1: Family Base Care and Social Policy: Recommendations for Change

FAMILY BASED CARE AND SOCIAL POLICY: RECOMMENDATIONS FOR CHANGE

The primary goals of this project were to explore factors that constrain family involvement in the care of a family member with a developmental disability and to identify new and improved means for overcoming such barriers. Findings stemming from various project activities strongly suggest that numerous aspects of present social policy* must be altered to encourage family-based care.

In this light, recommendations and proposals emerging from this project reflect a variety of ideas and concerns for improving present policy, examining unresolved conceptual issues, and securing needed information. The following recommendations are not in any particular order of priority:

1. Family support programs should be designed to empower families and persons with developmental disabilities.

An underlying theme of family support pertains to the role that consumers can play in the provision of care. A primary finding of this project is that family support programs should be designed in ways that:

- recognize the family's underlying commitment to care for their family member with a disability;
- embrace practices that promote, not discourage, increased family independence from the formal service system;

---

* As used here, a social policy option is defined as:

Something that could be done as a matter of national policy by way of position statement, set of principles, law, regulations, pattern of apropriation, or similar action on the part of any branch of government or a national public or private group so as to bring about more, more effective, better quality, easier, or more rewarding (to all parties) life as a family member by developmentally disabled persons. (Krantz, 1979; p. 104-105).

- take seriously the view of the family and the person with disabilities with regard to how services should be designed and rendered; and
- treat the person with developmental disabilities not as an passive recipient of services but as someone who has individual rights and who should participate in his or her own care to the extent feasible in order to develop as an informed self-advocate.

When these principles are used to guide program design, the family support system, while based on the aggregated need of all service consumers, is ultimately accountable to individual consumers. As such, it empowers families and persons with disabilities on two levels:

- Systems level: Service consumers have significant input into the substance, administration and planning of services; and
- Family level: Service consumers have some control over the services they receive. This suggests that flexible multiple service options should be available and that families and/or persons with disabilities be able to select services from a comprehensive service menu.

Some professionals warn that many family members and persons with disabilities are incapable of accepting an empowered role or want to be more dependent on outside direction. However, the absence of needed skills among some or the reluctance of others does not justify the substitution of professional judgement in all cases. To do so fosters dependence on professionals and discounts the potential of the family and persons with disabilities for making competent service related decisions.

Instead, service models must be founded on the assumption that all families and persons with developmental disabilities are potentially capable and willing to make responsible decisions; Families want the best for their members with disabilities. Given this presumption, the challenge for service planners is to establish partnerships among families, persons with developmental disabilities, and professionals that empower service consumers to the maximum feasible extent.

Of course, there are limits to the emotional, physical and financial resources of parents and their expertise. When first confronted with the advent of disability, many family members will have little understanding of what overall needs they will have. Moreover, even as time passes, some families will be unable or unwilling to accept an empowered role. Similarly, many persons with developmental disabilities will be unable to make responsible decisions in their own behalf. The eventual goal of the system, however, must be to equip service consumers, whether they are family members or persons with developmental disabilities, to provide and/or obtain competent care, not to ensnare them in bureaucratic mazes and to make them dependent on professional judgements.

2. **Family support programs should provide families with multiple service options.**

No two persons with developmental disabilities or two families are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions of the caregiving situation. Moreover, these factors are not static but evolve over time. These considerations suggest that responsive family support programs must permit a wide array of services and encourage each family to select those services that are most appropriate for its needs.

3. **Family support programs should make greater use of cash programs.**

Many states presently operate cash programs that provide families with money to offset the costs of providing care. To some extent, the effectiveness of these programs is dependent on the availability of needed services. Without such services, having money to spend will mean little to parents. Given an accessible array of services, however, these programs generally extend greater control to families over the services they receive. Even in states where systems of free in-kind supportive services also exist, cash programs allow parents to complement whatever services are available with others as needed. In essence, they represent a cost-effective and flexible means for states to accommodate the unique needs of individual families.

4. **Family support programs should make greater use of options under the Medicaid program.**

At least three options are available to states to neutralize existing Medicaid-based disincentives to family care: the Community Based Waiver Program, the Model Waiver Program, and Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982. These mechanisms allow modifications in deeming family income on behalf of children at risk of institutional placement for purposes of Medicaid eligibility. Efforts should be made to utilize these options to a greater extent. They should not, however, be thought of as ultimate solutions to the problem. Several analysts have argued that these solutions are temporary and that Medicaid policy as a whole must be reconceptualized. Recent discussion regarding the proposed Community and Family Living Act Amendments of 1985 (S. 873) serves notice that this process has already begun.

5. **Family support programs should make greater use of private sector resources.**

Certainly, private businesses cannot be expected to carry the entire burden for family support initiatives. Businesses have, however, shown some interest in allocating resources to complement services offered through the public sector. This interest could be promoted by: 1) establishing systematic procedures for businesses to contribute money to existing family support programs; 2) encouraging initiation of additional employer sponsored cash or fringe benefit programs for employees who have family members with disabilities; and 3) encouraging businesses to offer certain family support services of their own to complement existing public programs.

This latter suggestion is especially relevant to the health care industry. Government should act to encourage private health insurers to underwrite coverage for home health care. This could involve mandating that such coverage be made available as part of individual and/or group risk plans and establishing tax policy that provides incentives to insurers for providing such plans. It must be understood that the provision of suitable and affordable health care for persons with disabilities is an essential element of any family support system. To achieve this end, government and private insurers must work together as partners so that needed medical care will be within reach of all families.

6. Using tax policy to support families should be pursued with caution.

Though numerous incentives to encourage family based care could be provided through tax policy, these incentives must be viewed in light of their efficiency, effectiveness, and fairness. Using tax credits, tax exemptions or specialized tax relief to support individual families is questionable due to problems associated with: coordinating multiple levels of government, enforcing regulations, estimating costs in lost government revenue, establishing programs that are equitable to all income groups, and making programs easily accessible to families. Moreover, it should be understood that reducing potential tax liability is akin to providing parents with publicly financed cash assistance through the back door. This being the case, policy makers must decide if the most desirable means for providing such assistance is through tax policy.

In contrast, tax policy might be used with great effectiveness to encourage businesses to invest in family support services. As noted in an earlier recommendation, employers and private businesses -- especially those in the health services field -- might become actively involved with family support services if they were provided with some form of tax relief. This tactic should be pursued with care, however, given the need to coordinate private sector programs with those of the public sector and to assure the quality of private sector initiatives in the long term. This process could be facilitated if a working conference were held to delineate the steps that must be taken to establish effective public-private partnerships. Such a conference should include attendance by parents, government officials and private sector representatives.

7. Family support programs should make greater use of evolving computer technology.

Greater emphasis should be placed on using computer technology to assist parents. On a local level, computerized information networks could be established to encourage greater cooperation among families. For instance, listings of persons that could assist parents could be maintained and shared with parents as needed. Such persons could include qualified respite providers, building contractors experienced with removing home barriers, dentists or doctors who understand the special needs a person with disabilities may have, and other professionals whose services families may require. In addition, such networks could be used to manage information on special equipment or toys parents may wish to share or exchange with one another.

On a state or national level existing information systems, such as Project SHARE, could be utilized to foster more effective means of providing families with information pertaining to state-of-the-art instructional practices, useful state and federal tax relief programs, and novel private sector initiatives. This type information would help keep parents aware of what is available on a broader systems level as well as promote greater cooperation among caregiving families around the country.

Likewise, service planners and administrators could make greater use of computer based information systems. Computer technology can be used to guide development of resource allocation plans pertaining to family support, to track expenditures for such services, and to monitor the processes and outcomes of service provision.

8. **Development of parent-run mutual help organizations should be encouraged.**

Encouraging the development of parent-led mutual help groups will complement efforts to structure family support programs within a family empowerment model. Examples of such groups include those offering ongoing social support and advocacy training, and others involving joint estate planning. In addition, the need for providing support and information to other members of the immediate (e.g., siblings) and extended (e.g., grandparents) family should not be overlooked.

9. **Family support programs should be designed to make greater use of existing resources and facilities.**

It must be understood that developing family support systems does not necessarily imply a need for funding an entirely new and separate service system. Much can be done to build on existing resources. For instance, greater use can be made of public school facilities, community college campuses, community centers, church facilities, and other existing sites to serve as day care centers, recreational sites, evening respite centers, or training sites for persons with developmental disabilities and their family members.

Similarly, initiatives must be undertaken to encourage improved coordination between existing service providers such as public school teachers, family support providers, case consultants, medical care staff, vocational instructors, and specialized therapists (e.g., speech and physical therapists). None of these providers should work in a vacuum since the family must interact with each. Thus, care must be taken to coordinate the level, type, and content of services to maximize their combined effect. This issue takes on extraordinary importance during "transition periods" in the lives of the person with disabilities and his/her family (e.g., when the person with disabilities "ages out" of the public school system, when parents grow too old to provide home care, when the person with disabilities desires to move away from his/her family).

10. **Discussion should be encouraged between parents and professionals regarding unresolved conceptual and program design issues.**

Numerous issues pertaining to the overall concept and practice of family support remain unresolved. A series of structured forums should be held to examine more closely such issues as the purpose of family support programs, eligibility criteria, means of administration, and sources of funds. One outcome of such structured discussion could be the preparation of model legislation that could be used by states to guide development or improvement of family support programs.

11. A national study should be undertaken to identify the social and economic characteristics of families with members with developmental disabilities and to estimate their numbers.

Such information would benefit service planners by providing an improved understanding of the composition of caregiving families and knowledge regarding the overall number of families that could benefit from support services. This type of information could be acquired by surveying a systematic sample of families with members with developmental disabilities and could be achieved by adding a series of relevant questions to already planned federal surveys such as the Annual Housing Survey administered by the US Department of Housing and Urban Development. This type information, however, should not be collected in a sporadic or disjointed manner. Rather, there is a need for longitudinal studies that track these types of information over time and in relation to one another.

12. A study should be made of sociological and demographic trends related to the family's caregiving capability.

These trends include the number and type of surviving infants with disabilities, the size of families, and the number of women entering the work force. These trends should then be taken into account when outlining family support policy.

13. Ongoing evaluations of family support programs should be made a high priority.

U.S. Senator Patrick Moynihan recently noted that "social policy flows from social values, not social sciences." Given a societal commitment to support families, the purpose of program evaluation should not be to justify ongoing funding for family support but to determine what types of programs are most efficient and effective. Ideally, such research should be tied to specific models of family interaction. As relationships between family dynamics and the provision of family based care are understood, systematic programs could be designed to embellish family interactions concerning the family member with disabilities and improve the overall caregiving environment. In designing such programs, however, care should be taken not to exploit parents by expecting them to care for their offspring with disabilities indefinitely. All family care ends eventually. Thus, consideration must be given to how this natural transition can be best accommodated.

Moreover, such research can be used to help coordinate multiple funding sources or service providers. In the future, family support services will likely make use of multiple funding sources (e.g., the private and public sectors) and administrative formats (e.g., supportive services and cash programs). With experience and systematic study, the most beneficial formats may emerge. For instance, it may be found that certain services are best funded through the public sector. Likewise, the most beneficial administrative formats may also vary by service. Some service needs might best be met through direct cash grants to families. In contrast, other services might best be provided as free supportive services. In addition, it may be determined that certain system functions should be primarily state-directed, including needs assessment and evaluation, oversight, resource organization, and fund raising. In essence, research efforts must be directed at documenting the most efficient, effective, and equitable means for delivering family support services.

Conclusion

Findings emerging from this project reflect a growing concern with discovering ways to assist families who have a member with a developmental disability. This concern is expressed in efforts to understand more fully the varying and complex needs of families, and to implement comprehensive strategies for satisfying such needs. The above recommendations suggest that building an effective family support system will require the cooperation of many, including parents, immediate and extended family members, neighbors, government officials at all levels, and professionals working both in the public and private sector.

At the core of any effective family support system must be a firm societal resolve to actively encourage, rather than discourage, family care. This report presents evidence that such a commitment is emerging and that past biases in social policy and professional philosophy favoring out-of-home placement are coming under increasing scrutiny. Still in question are the respective roles families, persons with disabilities, and government should play in directing the course of family support services. History reveals that these roles seldom remain static but evolve continually with the social values of the times.

In addition, much must still be done to clarify the objectives of present family support initiatives, estimate the number of families that could be affected, resolve issues related to the administration and evaluation of statewide family support programs, and involve all aspects of the community -- including the private sector -- in promoting family care. It is our hope that this report and the above recommendations will provide needed information and stimulate further discussion among those concerned with encouraging and enhancing family care.

COMPOSITE BIBLIOGRAPHY

Abels, M. *Wisconsin voucher system initiative for long term support -- The consumer directed services project*. Materials Presented at a Research Update for the Office of Human Development Services of the Department of Health and Human Services, February 9, 1984.

Akabas, S.H. Workers are parents, too. *Child Welfare*, 1984, *63* (5), 387-399.

Akabas, S.H. & Krauskoff, M.S. *Families and work: Creative workplace responses to employees with disabled children*. New York, NY: Industrial Social Welfare Center, Columbia University, 1984.

Akabas, S.H. & Kurzman, P.A. *Work, workers and work organizations*. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1982.

Allen, J. The concept of vertical equity and its application to social program design. In P. Brown, C. Johnson, & P. Vernier (Eds.), *Income support: Conceptual and policy issues*. University of Maryland, Rowman and Littlefield, 1981.

Allen, M.K. Persistent factors leading to application for admission to a residential institution. *Mental Retardation*, 1972, *10*, 25-29.

Allin, R. & Allin, D. *The home intervention program*. Chesterfield, VA: Chesterfield Mental Health and Mental Retardation Services, undated.

ALMA Matters. Special toy libraries for children with disabilities. *Official Newsletter of the Alternative Living Managers Association* (1642 North Winchester Avenue, Suite 100, Chicago, IL), 1985, *1*(4), 1-2.

American Bar Association. *Guardianship and conservatorship: Statutory survey, model statue*. Paper presented by the Developmental Disabilities State Legislative Project of the American Bar Association Commission on the Mentally Disabled, June, 1979.

American Health Planning Association. *The complex cube of long term care: A national working conference*. Washington, DC: AHRA, 1984.

Annas, G. Denying the rights of the retarded: The Phillip Becker Case. *Hastings Center Report*, 1979, *9* (Dec.), 18-20.

Appell, M.J. & Tisdall, W.J. Factors differentiating institutionalized and non-institutionalized referred retardates. *American Journal of Mental Deficiency*, 1968, *73*, 424-432.

Apolloni, A.H. & Cooke, T.P. (Eds.). *A new look at guardianship*. Baltimore, MD: Paul Brooks Publishing, 1984.

Apolloni, A.H. & Triest, G. Respite services in California: Status and recommendations for improvement. *Mental Retardation*, 1983, *21*, 240-243.

Ashbaugh, J. & Allard, M. *Comparative analysis of the costs of residential and day services within institutional and community settings*. Boston, MA: Human Services Research Institute, 1983.

Ashbaugh, J.W. Comparative analysis of the costs of institutional and community settings. In J.W. Conroy and V.J. Bradley (Eds.), *The Pennhurst longitudinal study: A report of five years of research and analysis*. Philadelphia, PA: Temple University Developmental Disabilities Center. Boston, MA: Human Services Research Institute, 1985.

Association for Retarded Citizens in Colorado. *A plan to establish non-profit corporate guardianship and estate planning/management programs for Coloradans with developmental disabilities*. Denver, CO: Colorado Developmental Disabilities Council, 1983.

Association for Retarded Citizens National Insurance and Benefits Committee. *How to provide for their future*. Arlington, TX: ARC National Headquarters, 1984.

Bachrach, L.L. A Conceptual Approach to Deinstitutionalization of the Mentally Retarded: A Perspective from the Experience of the Mentally Ill. In R. Bruininks, C. Meyers, B. Sigford & C. Lakin (Eds.) *Deinstitutionalization and Community Adjustment of Mentally Retarded People*. Washington, DC: American Association on Mental Deficiency, 1981.

Balzano, M.P. & Beck, M.M. The social programs of organized labor. In J.A. Meter (Ed.), *Meeting human needs: Toward a new public philosophy*. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Bates, M. *State family support/cash subsidy programs*. Madison, WI: Wisconsin Developmental Disabilities Council, 1983.

Baumeister, A. The American residential institution: Its history and character. In A. Baumeister & E. Butterfield (Eds.), *Residential facilities for the mentally retarded*. Chicago: Aldine Publishing, 1970.

Bayley, M. Mental handicap and community care. London, United Kingdom: Routledge and Kegan Paul, 1973.

Beatrice, D. F. Case management: A policy option for long term care. Washington, DC: Health Care Financing Administration, 1980.

Beck, D. & Bradshaw, E. Marriage and the family under challenge: An outline of issues, trends, and alternatives. New York: Family Service Association of America, 1976.

Beckman-Bell, P. Parent perspectives. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt Rinehart, and Winston, 1981.

Berger, P. & Neuhaus, R. To empower people: The role of mediating structures in public policy. Washington, DC: American Enterprise Institute for Public Policy Research, 1977.

Birenbaum, A. On managing courtesy stigma. Journal of Health and Social Behavior, 1970, 11, 196-206.

Bird, C. Two-paycheck marriage: How women at work are changing life in America. New York: Rawson/Wade, 1979.

Bird, W.A. A survey of family support programs in seventeen states. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, 1984.

Blatt, B. In and out of mental retardation. Baltimore, MD: University Park Press, 1981.

Boggs, E.M. Feds and families: Some observations on the impact of federal economic policies on families with children who have disabilities. In M.A. Slater & P. Mitchell (Eds.), Family support services: A parent/professional partnership. Stillwater, OK: National Clearinghouse of Rehabilitation Training Materials, 1984.

Boggs, E.M. Behavioral fisics. in J.J. Bevilacqua (Ed.) Changing government policies for the mentally disabled. Cambridge, MA: Ballinger Publishing Co., 1981.

Boggs, E.M. Economic factors in family care. In R.H. Bruininks & G.C. Krantz (Eds.), Family care of developmentally disabled members: Conferences proceedings. Minneapolis, MN: University of Minnesota, 1979.

Boggs, E.M. & Henny, R.L. A numerical and functional description of the developmentally disabled population in the United States by major life activities as defined in the Developmental Disabilities Assistance and Bill of Rights of Act as Amended in P.L. 95-602. Philadelphia, PA: EMC Institute, 1979.

Bowe, R. Comback. New York, NY: Harper & Row Publishing, 1981.

Bradbury, K., Bishop, J., Garfinkel, I., Middleton, R. & Skidmore, F. Effects of welfare reform alternatives on the family. Washington, DC: Office of Income Security Policy, Department of Health and Human Services, 1977.

Bradley, V.J. Deinstitutionalization of developmentally disabled persons. Baltimore, MD: University Park Press, 1978.

Bradley, V.J. & Clarke, G. Paper victories and hard realities: The implementation of the legal and constitutional rights of the mentally disabled. Washington, DC: Health Policy Center, Georgetown University, 1976.

Braddock, D. Deinstitutionalization of the Retarded: Trends in Public Policy. Hospital and Community Psychiatry, 1981, 32, 607-615.

Braddock, D., Howes, R. & Hemp, R. Public expenditures. Chicago, IL: Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, 1984.

Braddock, D. Statement on S.2053: The community and family living amendments of 1983. Washington, DC: U.S. Senate Finance Committee, Subcommitte on Health, February 27, 1984.

Brown, P., Johnson, C. & Vernier, P. (Eds.). Income support: Conceptual and policy issues. College Park, MD: University of Maryland, Rowman and Littlefield, 1981.

Browning, R., Rhoades, C. & Crosson, A. Advancing your citizenship: Essays on consumer involvement of the handicapped. Eugene, OR: Rehabilitation Research and Training Center in Mental Retardation, 1980.

Browning, P., Thorin, E., & Rhoades, C. A national profile of self help/self advocacy groups of people with mental retardation. Mental Retardation, 1984, 22, 226-230.

Bruininks, R. Personal communication, unpublished data, 1983.

Bruininks, R.H., Hauber, F.A. and Kudla, M.J. National survey of community residential facilities: A profile of residences and facilities in 1977. Minneapolis, MN: University of Minnesota, Department of Psychoeducational Studies, 1979.

Bruininks, R.H. The needs of families. In R.H. Bruininks & G.C. Krantz, (Eds.) *Family care of developmentally disabled members: Conference proceedings*. Minneapolis, MN: University of Minnesota, 1979.

Bryce, M. Home-based care: Development and rationale. In S. Maybanks & M. Bryce (Eds.), *Home-based services for children and families*. Springfield, IL: Charles C. Thomas, 1979.

Bureau of Labor Statistics. *Autumn 1978 urban family budgets and comparative indexes for selected urban areas*. Washington, DC: U.S. Department of Labor, 1979.

Buscaglia, L. *The disabled and their parents. A counseling challenge*. Thorofare, NJ: Charles B. Slack, Inc. 1975.

Business Week. *The insurer's big push for home health care*. May 28, 1984, p. 128-130.

Caldwell, B. & Guze, S. A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. *American Journal of Mental Deficiency*, 1960, *64*, 845-861.

Callahan, J., Diamond, L. Giele, J. & Morris, R. Responsibilities of families for their severely disabled elders. *Health Care Financing Review*, 1980, *1*, 29-48.

Callahan, J.J., Plough, A.L. & Wisensale, S. *Long-term care of children*, University Health Policy Consortium. Waltham, MA: Brandeis University, 1981.

Carillo, A.C., Corbett, K. & Lewis V. *No more stares*. Berkeley, CA: Disability Rights Education and Defense Fund, Inc. 1983.

Carr, C. *Independent living and advocacy base of service provider*. Rehabilitation Gazette, 1983, *25*, 42-43.

Caro, F.G. *Care for the disabled: Family and public responsibilities*. New York, NY: Institute for Social Welfare Research, Community Service Society, 1980.

Carver, J. *Reactions of parents of severely retarded children at a state training school*. Unpublished doctoral dissertation, Yale University, 1956.

Castellani, P.J. and Puccio, P.S. *The Development of Family Support Services for the Developmentally Disabled: An Administrative and Political Perspective*. Paper Presented at the American Society for Public Administration National Conference, Denver, CO, 1984.

Center for Life Independent Living, Inc. & Closer Look (Ed.) *Taking charge of your life*, Washington, DC: Closer Look, 1981.

Cianci, V. Home taining for retarded children in New Jersey. *The Training School Bulletin*, 1951, *48*, 131-139.

Close, D.W. Community living for severely and profoundly retarded adults: A group home study. *Education and Training of the Mentally Retarded*, 1977, *12*, 256-262.

Close, D.W., Irvin, L.K., Taylor, V.E. & Agosta, J.M. Community living skills instruction for mildly retarded persons. *Exceptional Children Quarterly*, 1981, *2*(1), 75-85.

Cobb, S. Social support as a moderator of life stress. *Psychosomatic Medicine*, 1976, *38*, 300-314.

Cohen, S. *Demonstrating model continua of respite care and parent training services for families of persons with developmental disabilities*. Unpublished annual report, 1979. (available from United Cerebral Palsy Associations, Inc.).

Commission on Quality of Care for the Mentally Disabled (NYS) *Promoting Equity in the Family of New York: A Review of Outpatient Services for Developmentally Disabled People*. Albany, NY: Office of Mental Retardation and Developmental Disabilities, 1984.

Conroy, J.W. & Bradley, V.J. *The Pennhurst longitudinal study: A report of five years of research and analysis*. Philadelphia, PA: Temple University Developmental Disabilities Center, Boston, MA: Human Services Research Institute, 1985.

Copeland, W.C. & Iverson, I.A. Not just the aged, not just health care, and not just nursing homes: Some proposals for policy and legislative changes in long-term care. In J.J. Bevilacqua (Ed.), *Changing government policies for the mentally disabled*. Cambridge, MA: Ballinger Publishing Company, 1981.

Crnic, K.A., Friedrich, W.N. & Greenberg, M.T. Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency*, 1983, *88*, 125-138.

Cronbach, L. & Furby, L. How should we measure "change" -- or should we? *Psychological Bulletin*, 1970, *74*, 68-80.

CSR. *Alternative mechanisms for financing public social services: Final report*. Washington, DC: Department of Health and Human Services, Assistant Secretary of Planning and Evaluation, Contract No. 100-82-0028, 1983.

Culver, M. *Intergenerational social mobility among families with a severely mentally retarded child*. Unpublished doctoral dissertation, University of Illinois, 1967 (available from University of Illinois library).

Daniels, M. Conflicting objectives and the priorities problem. In P. Brown, C. Johnson, & P. Vernier (Eds.), *Income support conceptual and policy issues*. University of Maryland: Rowman and Littlefield, 1981.

Davidson, B. & Dosser, D. A support system for families with developmentally disabled infants. *Family Relations*, 1982, *31*, 295-299.

Davis, C.G. Financial and estate planning for parents of a child with handicaps. *Western New England Law Review*, 1983 *5*(3), 495-535.

de Bevoir, S. *The coming age*. New York, NY: G.P. Putnams & Sons, 1972.

Demos, J. Family home care: Historical notes and reflections. In R. Perlman (Ed.), *Family home care: Critical issues for services and policies*. New York: The Haworth Press, 1983.

Developments in the law--the Constitution and the family. *Harvard Law Review*, 1980, *93*(6), 1-229.

Division of Educational Services. *Sixth annual report to Congress on the implementation of Public Law 94-142*. Washington, DC: U.S Department of Education, Office of Special Education and Rehabilitation Services, 1984.

Doll, W. Family coping with the mentally ill: An unanticipated problem of deinstitutionalization. *Hospital and Community Psychiatry*, 1976, *27*, 183-185.

Downey, K.J. Parent's reasons for institutionalizing severely mentally retarded children. *Journal of Health and Human Behavior*, 1965, *6*, 163-169.

Dunlap, W.R. Services for families of the developmentally disabled. *Social Work*, 1976, *21*, 220-223.

Dunlap, W.R. & Hollingsworth, J.S. How does a handicapped child affect the family? Implications for pratitioners. *The Family Coordinator*, 1977, *26*, 286-293.

Duvall, E. *Marriage and family development*. New York: Harper and Row, 1977.

Dworkin, S. Notes on Carter's family policy: How it got that way, what happened to his White House conference, and some warnings for the future. *MS*, 1978, *7*(61), 61-63.

Dywbad, G. *The mentally retarded child under five*. Arlington, TX: Association for Retarded Citizens, 1966.

Edwards, B. & Mandeville, W. *Tax exemptions for persons with disabilities*. Raleigh, NC: Evaluation Unit, State of North Carolina Council on Developmental Disabilities, 1982.

Engelmann, S. & Carnine, D. *Theory of instruction: Principles and application*. New York, NY: Irvington Publishers, 1982.

English, R.W. & Olson, K.K. Parenting Handicapped children: Their earliest experiences. *The Journal for Special Education*, 1978 *15*(1), 10-17 and 15(2), 169-186.

Evans, I.M. & Meyer, L.H. *An educative approach to behavior problems*. Baltimore, MD: Paul Brookes Publishing, Co., 1984.

Farber, B. *Mental retardation: Its social context and social consequences*. Boston, MA: Houghton Mifflin, 1968.

Farber, B. Sociological ambivalence and family care: The individual proposes and society disposes. In R. Perlman, (Ed.), *Family home care: Critical issues for services and policices*. New York, NY: The Haworth Press, 1983.

Farber, B. Sociological ambivalence and family care. In R. Bruininks & G. Krantz (Eds.), *Family care of developmentally disabled members: Conference proceedings*. Minneapolis: University of Minnesota, 1979.

Farber, B. & Jenne, W.C. Interaction with retarded siblings and life goals of children. *Journal of Marriage and Family*, 1963, *25*, 96-98.

Featherstone, J. (1979). Family matters. *Harvard Educational Review*, *4*[illegible](1), 20-52.

Fernald, C.D. *Too Little Too Late: Deinstitutionalization and the Development of Community Services for Mentally Retarded People*. Chapel Hill, NC: Bush Institute for Child and Family Policy, University of North Carolina, September 1984.

Fortier, L.M. & Wanlass, R.L. Family crisis following the diagnosis of a handicapped child. *Family Relations*, 1984, *33*(1), 13-24.

Fotheringham, J.B., Skelton, M. & Hoddinot, B.A. The effects on the family of the presence of a mentally retarded child. *Canadian Psychiatric Association Journal*, 1972, *17*, 283-290.

Fotheringham, J. & Creal, D. Handicapped children and handicapped families. *International Review of Education*, 1974, *20*, 355-373.

Freedman, D., Fox-Kolenda, B. & Brown, S. A multihandicapped rubella baby: The first eighteen months. *Journal of the American Academy of Child Psychiatry*, 1970, *9*, 298-317.

Friedman, W. *Winning the real war*. Rehabilitation Gazette, 1980, *23*, 13-14.

Friedrich, W. Predictors of the coping behaviors of mothers of handicapped children. *Journal of Consulting and Clinical Psychology*, 1979, *47*, 1140-1141.

Gaiter, D. Siblings who help disabled. *The New York Times*, July 2, 1984, p. 18.

Gardner, J.F. & Markowitz, R.K. *Maryland family support services consortium: Data analysis summary, year one report*. Baltimore, MD: Maryland Developmental Disabilities Council, 1984.

General Accounting Office. *Assessment of the use of tax credits for families who provide health care to disabled elderly relatives*. Washington, D.C.: GAO, Document Handling and Information Services Facility: IPE-82-7, 1982.

Gettings R.M. *Federal financing of services to mentally retarded persons: Current issues and policy options*. Paper prepared for U.S. Office of Human Development Services, 1980.

Giele, J.Z. *A review of selected data sources on the family's role in long-term care*. Waltham, MA: Brandeis University, Levinsion Policy Institute, 1981.

Gilbert, N. Special issue of family policy. *Social Work*, 1979, *24*,(6), 445-572.

Gliedman, J. & Roth, W. *The unexpected minority: Handicapped children in America* (Summary). New York, NY: Harcourt, Brace and Javanovich, 1980.

Goldman, H.H. Mental illness and family burden: A public health perspective. *Hospital and Community Psychiatry*, 1982, *33*, 557-560.

Gollay, E., Freedman, R. Wyngaarden, M. & Kurtz, N.R. *Coming Back*. Cambridge, MA: Abt Books, 1978.

Goode, W.J. *The family*. Englewood Cliffs, NJ: Prentice-Hall, 1964.

Gordon, S. *Living fully: A guide for young people with a handicap their parents, their teachers and professionals*. New York, NY: John Day, 1975.

Gottleib, J. Public, peer and professional attitudes toward mentally retarded persons. In M. Begab & S. Richardson (Eds.), *The mentally retarded and society: A social science perspective*. Baltimore, MD: University Park Press,. 1975.

Graliker, B., Fisher, K. & Koch, R. Teenage reactions to a mentally retarded sibling. *American Journal on Mental Deficiency*, 1962, *67*,(5), 740-747.

Graliker, B.V. & Koch, R. A study of factors influencing placement of retarded children in a state residential institution. *American Journal of Mental Deficiency*, 1965, *69*, 553-559.

Griss, R. *The role of vouchers in long term support*. Paper written under contract to the Wisconsin Department of Health & Social Services, Division of Community Services, Office of Program Initiatives, 1984.

Grossman, F. *Brothers and sisters of retarded children*. Syracuse, NY: Syracuse University Press, 1972.

Gruenberg, L.W. & Pillemer, K.A. Disability allowance for long term care. In J.J. Callahan & S.S. Wallack (Eds). *Reforming the long-term care system*. Lexington, MA: Lexington Books, 1981.

Gruppo, P. Helping the handicapped child. *Journal of Practical Nursing*, 1978, 30-37.

Hall, R.V. & Hall, M.C. *How to teach series* (16 pamphlets). Austin, TX: Pro-Ed, 1980.

Halpern, R. Lack of effects for home-based early intervention?: Some possible explanations. *American Journal of Orthopsychiatry*, 1984, *54*(1), 33-42.

Hart, A.F. Policy responses to schizophrenia: Support for the vulnerable family. In R. Perlman (Ed.), *Family home care: Critical issues for services and policies*. New York, NY: The Haworth Press, 1983.

Hauber, F.A., Bruininks, R.H., Hill, B.K., Lakin, K.C. & White, C.C. *National census of residential facilities: Fiscal Year 1982*. Minneapolis: University of Minnesota, Department of Educational Psychology, 1982.

Hawkins, R. Developing comprehensive emergency services. In S. Maybanks & M. Bryce (Eds.), *Home-based services for children and families: Policy, practice, and research*. Springfield, IL: Charles C. Thomas, 1979.

Heifetz, L. Professional preciousness and the evaluation of parent training strategies. In P. Mittler (Ed.), Research to practice in mental retardation, 1. Baltimore: University Press, 1977.

Heisler, V. A handicapped child in the family. New York: Grune & Stratton, 1972.

Herman, S.E. Family support services: Reports on meta-evaluation study. Lansing, MI: Michigan Department of Mental Health, 1983.

Herr, S.S. The Phillip Becker case resolved: A chance for habilitation. Mental Retardation, 1984, 22, 30-35.

Hill B., & Lakin, K.C. Trends in residential services for mentally retarded people: 1977-1982 (Brief # 23). Minneapolis: Center for Residential and Community Services, University of Minnesota, Department of Educational Psychology, 1984.

Hill R. Families under stress. New York: Harper & Row, 1949.

Hobbs, N. The future of children. San Francisco, CA: Jossey-Bass, 1974.

Horejsi, C.R. Social and psychological factors in family care. In R.H. Bruininks & G.C. Krantz (Eds.), Family care of developmentally disabled members: Conference proceedings. Minneapolis, MN: University of Minnesota, 1979.

Horejsi, C.R. Social and psychological factors in family care. In Perlman, R. (Ed.), Family home care: Criteria issues for services and policies. New York, NY: The Haworth Press, 1983.

Human Services Research Institute. Assessing and enhancing the quality of human services. Boston, MA: Human Services Research Institute, 1984.

Intagliata, J. Improving the quality of community care for the chronically mentally disabled: The role of case management. Schizophrenia Bulletin, 1982 8(4), 655-674.

Intagliata, J., Kraus, S., & Willer, B. The Impact of Deinstitutionalization on a Community-Based Service System. Mental Retardation, 305-307, 1980.

Ivie, P. A right, not a favor- a legal right handbook for the developmentally disabled. Tuscaloosa, AL: Alabama Department of Disabilities Advocacy Programs, 1978.

Jacobson, J.W. & Janicki M.P. Observed prevalence of multiple developmental disabilities. *Mental Retardation*, 1983, *21*, 87-94.

Janicki, M.P. *Etiological factors as determinants of institutional or alternative care placements, and in home retention of retarded persons*. Albany, NY: New York State Office of Mental Retardation/Developmental Disabilities, 1981.

Jefferson, E. & Baker, D. The needs of the handicapped child in the Sheffield area. *Handicapped children and their families*. Dun fermline, Scotland, 1964.

Johnson, C. Equity: Its scope and its relation to other objectives. In P. Brown, C. Johnson, & P. Vernier (Eds.), *Income support conceptual and policy issues*. College Park, MD: University of Maryland, Rowman and Littlefield, 1981.

Justice, R.S. Foster family care for the retarded: Management conce§ns of the caretaker. *Mental Retardation*, 1971, *9*, 12-15.

Justice, R.S., Bradley, J. & O'Connor, G. Foster family care for the retarded: Management concerns of the caretaker. *Mental Retardation*, 1971, *9*, 12-15.

Kadushin, A. *Child welfare services* (3rd Edition). New York, NY: Macmillan Publishing Co., 1980.

Kane, R.L. and Kane, R.A. Care of aged: Old problems in need of new solutions. *Science*, 1978, *20* (May 6) 913-919.

Karnes, M.B. & Teska, J.A. Toward successful parent involvement in programs for handicapped children. In J.J. Gallagher (Ed.), *New directions for exceptional children: Parents and families of handicapped children*. San Francisco, CA: Jossey-Bass, Inc., 1980.

Kendall, D. & Calmann, E. Handicapped children and their families. A survey based on Shropshire and West Midland Counties. *Handicapped children and their families*. Dun fermline, Scotland, 1964.

Keniston, K. & The Carnegie Council on Children. *All our children: The America family under pressure*. New York, NY: Harcourt, Brace, Javanovich, 1977.

Kiely, M. & Lubin, R.A. *Estimating the prevalence of persons with developmental disabilities in New York State*. Staten Island, NY: New York State Institute for Basic Research in Developmental Disabilities, 1983.

Kinney, J., Madsen, B., Fleming, T. & Hacipoila, D. Homebuilders: Keeping families together. *Journal of Consulting and Clinical Psychology*, 1977, *45*, 667-673.

Klerman, L.V. Adolescent mothers and their children: Another population that requires family care. In R. Perlman (Ed.), *Family home care: Critical issues for services and policies*. New York, NY: The Harworth Press, 1983.

Konanc, J.T. & Warren, N.J. Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. *Family Relations*, 1984, *33*(1), 135-142.

Kozak, A.E. & Marvin, R.S. Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. *Family Relations*, 1984, *33*(1), 67-78.

Lakin, K.C., Hill, B., Hauber, F., Bruininks, R. & Heal, L. New admissions and readmissions to a national sample of public residential facilities. *American Journal on Mental Deficiency*, 1983, *88*, 13-20.

Lakin, C.K., Bruininks, R.H., Doth, D., Hill, B. & Hauber, F. *Sourcebook on long term care for developmentally disabled people*. Minneapolis, MN: University of Minnesota, Department of Psychology, 1982.

Lash, M. *Respite care: The development of a preventive support service for families under stress*. Boston: Massachusetts Department of Social Services, 1983.

Laswell, H.D. *Politics: Who gets what, when, how*. New York, NY: McGraw-Hill, 1936.

Lea, S., Reed, R.R. & Hansen, R.F. *Developmentally disabled persons of normal intelligence: Need assessment findings*. San Mateo, CA: UCPA of California, 1978.

Legislative Commission on Expenditure Review (New York State) LCER. *Mental Health Community Support System*, Albany, NY: Program Audit, October, 1983.

Leslie, G.R. *The family in social context* (4th Ed.) New York: Oxford University Press, 1976.

Lipman-Bluman, J. A crisis framework applied to macrosociological family changes. *Journal of Marriage and the Family*, 1975, *27*, 889-902.

Lonsdale, G. Family life with a handicapped child: The parents speak. *Child Care, Health and Development*, 1978, *4*, (2), 99-120.

Loop, B. & Hitzing, W. Family resource services and support systems for families with handicapped children. In J. Stark (Ed.), Family resource systems: The Nebraska model. Omaha, NE: Nebraska Governor's Planning Council on Developmental Disabilities, 1980.

Longo, D.C. & Bond, L. Families of the handicapped child: Research and practice. Family Relations, 1984, 33,(1), 57-66.

Lowi, The end of liberalism, (2nd Ed.) New York, NY: W.W. Norton, 1979.

Lubin, R.A., Jacobson, J.W., & Kiley, M. Projected impact of the functional definition of developmental disabilities: The categorically disabled population and service eligibility. American Journal of Mental Deficiency, 1982 87, 73-79.

MacEachron, A.E. & Krauss, M.W. A national survey of handicapped children receiving public social services: Prevalance rates and service patterns in 1977. Children and Youth and Services Review, 1983, 5, 117-134.

Mahoney, K.J. A national perspective on community differences in the interaction of the aged with their adult children. Madison, WI: Unversity of Wisconsin at Madison, Fay McBeath Institute, 1977.

Mason, B. & Mason, A. Constitutional issues for families in Nebraska. In J.A. Stark (Ed.), Family resource systems: The Nebraska model. Omaha, NE: Nebraska Governor's Planning Council on Developmental Disabilities, 1980.

McAndrew, I. Children with a handicap and their families. Child: Care, Health and Development, 1976, 2, 213-237.

McCubbin, H. & Figley, C. Stress and the family, Volume 1: Coping with normative transitions. New York: Brunner/Mazel, Inc., 1983.

McCubbin, H., Joy, C., Cauble A., Comeau, J., Patterson, J. & Needle, R. Family stress and coping: A decade review. Journal of Marriage and the Family, 1980, 42,(4), 855-871.

McCubbin, H.J. Integrating coping behavior in family stress theory. Journal of Marriage and Family, 1979, 41, 237-244.

McDaniel, J. Physical disability and human behavior. New York, NY: Pergamon Press, 1969.

McDonald, G. & Nye, F. Family policy. Minneapolis: National Council on Family Relations, 1979.

McGrath, M. *Give us the knife -- carving a lifestyle.* Nashville, TN: Ashlar Press, 1978.

McKinnon, V.R., Samors, P.W. & Sullivan, S. Business initiatives in the private sector. In J.A. Meyers (Ed.), *Meeting human needs: Toward a new public philosophy*. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Meiners, M.R. *Private coverage of services not covered by medicare: The case for long term care insurance*. Paper presented at the 110th annual meeting of the American Public Health Association, 1982.

Meyers, J.A. *Meeting human needs: Toward a new public philosophy*. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Michigan House Legislature Analysis Section. *Second analysis of House Bill 4488: Mental health, family support subsidy*. Michigan State Legislature, 1983.

Minde, K., Hackett, J., Killou, D. & Sliver, S. How they grow up: 41 handicapped and their families. *American Journal of Psychiatry*, 1972, *128*, 1554-1560.

Mink, I.T., Meyers, C.E. & Nihara, K. Taxonomy of familiy styles: II. Homes with slow children. *American Journal of Mental Deficiency*, 1984, *89*, 111-123.

Minnesota Developmental Disabilities Council. *Policy analysis no. 18: The Minnesota family subsidy programs: Its effects on families with a developmentally disabled child*. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1983a.

Minnesota Developmental Disabilities Council. *Developmental disabilities and public policy: A review for policymakers*. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1983b.

Minnesota Developmental Disabilities Council. *Toward a developmental disabilities policy agenda: Assuring futures of quality*. St. Paul, MN: Minnesota Developmental Disabilities Planning Council, 1984.

Moore, J.A., Hamerlynck, L.A., Barsh, E.T., Spieker, S. & Jones, R. *Extending family resources* (2nd Ed.). Seattle, WA: Children Clinic and Preschool, 1982.

Moroney, R.M. Allocation of resources for family care. In R.H. Bruininks & G.C. Krantz (Eds.), *Family care of developmentally disabled members: Conference proceedings*. Minneapolis, MN: University of Minnesota, 1979.

Moroney, R.M. Public social policy: Impact on families with handicapped children. In J.L. Paul (Ed.), Understanding and working with parents of children with special needs. New York, NY: Holt, Rhinehart and Winston, 1981a.

Moroney, R.M. Mental disability: The role of family. In J.J. Bevilacqua (Ed.), Changing government policies for the mentally disabled. Cambridge, MA: Ballinger Publishing Company, 1981b.

Moroney, R.M. Families, care of the handicapped, and public policy. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York: The Haworth Press, 1983.

Michigan Association of Community Mental Health Boards. Family support services: A nationwide resource guide. Lansing, MI: Michigan State Planning Council for Developmental Disabilities, Michigan Department of Mental Health, 1983.

Morell, B.B. Deinstitutionalization: Those left behind. In R.H. Perlman (Ed.), Family home care: Critical issues for services and policies. New York, NY: The Haworth Press, 1983.

National Association of State Mental Retardation Program Directors. Middle income families find support. New Directions, 1984, 14(11), 1,3.

National Association of State Mental Retardation Program Directors (NASMRPD). The Minimal Array of Essential Services for Mentally Retarded Persons. Alexandria, VA: National Association of State Mental Retardation Program Directors, 1979.

Nebraska Legislative and Advocacy Committee. A summary of family assistance legislation in seven states. Nebraska Governor's Planning Council on Developmental Disabilities, 1980.

Neff, W. & Weiss, S. In B. Wolman (Ed.), Handbook of clinical psychology. New York: McGraw-Hill, 1965.

The New York Times, June 10, 1984, p. 1.

New York Times, Doctor assails Reagan on care of mentally ill. July 8, 1984.

New York Times, Who'll pay the bills for Baby Doe? July 9, 1984.

New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). Local Services Project: The Provision of Planning of Support Services Phase I Report. Albany, NY: Office of MR/DD, 1983.

Nihira, K., Meyers, C.E., & Mink, I.T. Relationship between home environment and school adjustment of TMR children. American Journal of Mental Deficiency, 1981, 86, 8-15.

Nihira, K., Meyers, C.E. & Mink, I.T. Reciprocal relationship between home environment and development of TMR adolescents. American Journal of Mental Deficiency, 1983, 88, 139-149.

Nijre, B. (1969). The principle of normalization and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services, for the mentally retarded. Washington, DC: Government Printing Office, 255-287, 1981.

Noble, J.H. New directions for public policies affecting the mentally disabled. In J.J. Bevilacqua (Ed.), Changing government policies for the mentally disabled. Cambridge, MA: Ballinger Publishing Company, 1981.

Office of Information and Resources for the Handicapped. Directory of national information sources on handicapping conditions and related services. Washington, DC: Superintendent of Documents, U.S. Government Printing Office (Publication No. E-82-22007), 1982.

O'Leary, K., O'Leary, S. & Becker, W. Modification of a deviant sibling interaction pattern in the home. Behavior Research and Therapy, 1967. 5, 113-120.

Ozawa, M. Income maintenance and work incentives. New York: Praeger Publishers, 1982.

Patterson, J. & McCubbin, H. Chronic illness: Family stress and coping. In C. Figley & H. McCubbin (Eds.), Stress and the family: Volume II. Coping with catastrophy. New York: Brunner/Mazel, Inc., 1983.

Paul, J. & Porter P. Parents of handicapped children. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart, and Winston, 1981.

Penner, R.G. Macroeconomic and tax policy environment for private sector initiatives. In J.A. Meyer (Ed.), Meeting human needs: Toward a new public philosophy. Washington, DC: American Enterprise Institute for Public Policy Research, 1982.

Perlman, R. (Ed.) Family home care: Critical issues for services and policies. New York, NY: The Haworth Press, 1983.

Perlman, R. Use of the tax system in home care: A brief note. In R. Perlman (Ed.), *Family home care: Critical issues for services and policies*. New York, NY: The Haworth Press, 1983.

Perlman, R. & Giele, J.Z. An unstable triad: Dependent's demands, family resources, community supports. In R. Perlman (Ed.), *Family home-based care: Critical issues for services and policies*. New York, NY: The Haworth Press, 1983.

Piccione, J. *Homemaker, volunteers, and taxes: Two proposals for examiniation*. Washington, D.C.: Free Congress Research and Education Foundation, 1982(a).

Piccione, J. *The human services option: New funding for the charitable sector*. Washington, D.C.: Free Congress Research and Education Foundation, 1982(b).

Poznanski, E. Emotional issues in raising handicapped children. *Rehabilitation Literature*, 1973, *34*, 322-326.

Pullo, M. & Hahn, S. *Respite care: A family support service*. Madison, WI: United Cerebral Palsy of Wisconsin, 1979.

Rosenau, N. *Final evaluation of family support program*. Macomb-Oakland, MI: Macomb County Community Mental Health and Macomb-Oakland Regional Center, 1983.

Russel, L.M. *Alternatives: A family guide to legal and financial planning for the disabled*. Evanston, IL: First Publications, 1983.

Sager, A. Who should control long-term planning for the elderly. In R. Perlman, (Ed.), *Family home care: Critical issues for services and policies*. New York, NY: The Haworth Press, 1983.

Scheerenberger, R. *Public residential services for the mentally retarded in 1979*. Madison, WI: Central Wisconsin Center for the Developmentally Disabled, 1979.

Scheerenberger, R. *Current Trends and Status of Public Residential Services for the Mentally Retarded*. Madison, WI: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1975.

Schield, S. The family of the retarded child. In R. Koch & J. Dobson (Eds.), *The mentally retarded child and his family: A multidisciplinary handbook*. New York: Brunner/Mazel, Inc, 1976.

Schwartz, S.R., Goldman, H.H. and Chrugin, S. Case management for the chronically mentally ill: Models and dimensions. *Hospital and Community Psychiatry*, 1982, *33*(12), 1006-1009.

Senate Standing Commitee on Health and Welfare. Report on mentally and physically handicapped persons in Australia. Commonwealth Government Printing Office, Canberra, 1971.

Shapiro, J. Family reactions and coping strategies in response to the physically ill or handicapped child: A review. Social Science Medicine, 1983, 17(14), 913-931.

Shellhaas, M.D. & Nihira, K. Factor analysis of reasons retardate are referred to an institution. American Journal of Mental Deficiency, 1969, 74, 171-179.

Sherman, B.R. & Cocozza, J.J. Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. Family Relations, 1984, 33,(1), 95-104.

Skarnulis, E. Noncitizen: Plight of the mentally retarded. Social Work, 1974, Jan., 56-72.

Skarnulis, E. Less restrictive alternatives in residential services. AAESPH Review, 1976 1(3), 40-84.

Snell, M.E. & Beckman-Brindley, S. Family involvement in intervention with children having severe handicaps. TASH, 1984, 9, 213-230.

Sokol-Kessler, L., Conroy, J., Feinstein, [illegible]., Lemanowicz, J., & McGurrin, M. Development progress in institutional and community settings. TASH, 1983, 8, 43-48.

Stabenow, D. The family support subsidy, act: Questions and answers on P.A. 249 of 1983 (H.[illegible] 4448). Lansing, MI: 412 Roosevelt Building, State Capitol, 1983.

Stuemke, J.E. Estate planning for families with developmentally disabled children. In T. Apolloni & T. Cooke (Eds.), A new look at guardianship. Baltimore, MD: Paul Brookes Publishing, 1984.

Suelzle, M. & Keenan, V. Changes in family support networks over the life cycle of mentally retarded persons. American Journal of Mental Deficiency, 1981, 86, 267-274.

Surrey, S.S. Pathways to tax reform: The concept of tax expenditures. Cambridge, MA: Harvard University Press, 1973.

Symposium on Living Independently With Severe Disability, Personal Assistants. Paper presented at the second Post Polio Conference, May 1983.

Tapper, H. Barriers to a family subsidy program. In R.H. Bruininks & G.C. Krantz (Eds.), *Family care of developmentally disabled members: Conference Proceedings*. Minneapolis, MN: University of Minnesota, 1979.

Task Force on Concerns of Physically Disabled Women. *Toward intimacy*. Everett, WA: Planned Parenthood of Snohomish County, 1977.

Tausig, M. & Epple, W. *Placement Decision-Making: A Study of Factors that Lead to Out-of-Home Placement*. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, Study Report 82-01, 1982.

Tausig, M. *Factors in family placement decision-making for disabled individuals*. Albany, NY: Program Research Unit Office of Mental Retardation and Developmental Disabilities, 1983.

Tausig, M. Factors in family decision-making about placement for developmentally disabled individuals. *American Journal of Mental Deficiency*, 1985, *89*, 352-361.

Tew, B. & Lawrence K. Mothers, brothers, and sisters of patients with spina bifida. *Developmental Medicine and Child Neurology*, 1973, *15* (Supplemental Number 29), 69-78.

Thorsson, I. Children's allowance in Sweden. In E. Burns (Ed.), *Children's allowances and the economic welare of children*. New York: Citizen's Committee for Children of New York City, 1968.

Trace, M. & Davis, M. Restrictiveness in the doctrine of the least restrictive alternative: An operational approach. Unpublished manuscript, Ellsworth College, undated.

Turnbull, H.R. Parents and the law. In J. Paul (Ed.), *Understanding and working with parents of children with special needs*. New York: Holt, Rinehart & Winston, 1981.

Turnbull, A., Strickland, B. Parents and the education system. In J. Paul (Ed.), *Understanding and working with parents of children with special needs*. New York: Holt, Rinehart, and Winston, 1981.

Turnbull, A., Summers, J. & Brotherson, M. Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J. Gallagher & P. Vietze (Eds.), *Research on families with retarded children*. Baltimore: University Park Press, in press.

Turnbull, H.R., Brotherson, M.J. & Summers, J.A. The impact of deinstitutionalization on families: A family systems approach. In R.H. Bruininks and K.C. Lakin (Eds.), Living and learning in the least restrictive environment. Baltimore, MD: Paul Brookes Co., 1985.

U.S. Bureau of the Census. Population profile of the United Stats: 1982, Current Population Reports, Special Studies, Series P-23, No. 130, 1984.

U.S Bureau of the Census. Statistical Abstract of the United States: 1978 and 1981.

Vitello, S. The institutionalization and deinstitutionalization of the mentally retarded in the United States. In L. Mann & D. Sabatino (Eds.), The third review of special education. New York: Grune & Stratton, 1976.

Waisbren, S. Parent reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency, 1980, 34, 345-351.

Warren, R.D. & Dickman, I.R. For this relief (respite), much thanks . . . New York, NY: United Cerebral Palsy Associations, Inc., 1981.

Wares, M. & Bentley, A. Report on the evaluation of the Alabama developmental disabilities advocacy program. Tuscolosa, AL: Alabama Developmental Disabilities Advocacy Programs, 1982.

Weiner, H., et al. The world of work and social welfare policy. New York, NY: Industrial Social Welfare Center, Columbia University, 1972.

Weiss, H. Issues in the evaluation of family support and education programs. Family Resource Coalition Report, 1983, 2(4), 10-11.

Wieck, C.A. & Bruininks, R.H. The cost of public and community residential care for mentally retarded people in the United States. Minneapolis, MN: University of Minnesota, Department of Psychoeducational Studies, 1980.

Wikler, L. Chronic stress of families of mentally retarded children. Family Relations, 1981, 30, 281-288

Wikler, L. & Hanusa, D. The impact of respite care on stress in families of mentally retarded children. Paper presented at Amercian Association of Mental Deficiency, San Francisco, May, 1980.

Wikler, L. Chronic stress of families of mentally retarded children. In D.H. Olson & B.C. Miller (Eds.), *Family studies review yearbook* (Vol 1). Beverly Hills, CA: Sage Publications, 1983.

Wildavsky, A. *The Politics of the Budgetary Process*. Boston, MA: Little Brown, 1964.

Willer, B. & Intagliata, J. *Promises and realities for mentally retarded citizens: Life in the community*. Baltimore: University Park Press 1984.

Wright, L. Counseling with parents of chronically mentally ill children. *Postgraduate Medicine*, 1970, 173-176.

Wolfensberger, W. *Normalization*. Toronto, Canada: National Institute of Mental Retardation, 1972.

Wolfensberger, W. *The nature and origin of our institutional models*. Syracuse, NY: Human Policy Press, 1975.

Younghusband, E., Birchall, D., Davie, R. & Kellmar, M. (Eds.). *Living with handicap*. London: National Bureau for Cooperation in Child Care, 1970.

Zimmerman, S.L. The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. *Family Relations*, 1984, *33*(1), 105-118.

Zuckerman, H.S. Industrial rationalization of a contract industry: Multi-institutional hospital systems. *Annals of the American Academy of Political and Social Sciences*, 1983 (July), 4, 216-230.

APPENDIX A: LIST OF CONFERENCE PARTICIPANTS

John Agosta, Ph.D.
Research Associate
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Mary Ann Allard
Research Associate
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Tony Apolloni, Ph.D.
Executive Director
California Institute on Human Services
Sonoma State University
Rohnert Park, CA 94928

Allan Bergman
Executive Director
Colorado Association for
Retarded Citizens
2727 Bryant Street, Suite L-3
Denver, CO 80211

Joseph Bevilacqua, Ph.D.
Commissioner
Department of Mental Health
and Mental Retardation
PO Box 1797
Richmond, VA 23214

Valerie J. Bradley
President
Human Services Research Institute
120 Milk Street (8th Floor)
Boston, MA 02109

Allan Carlson, Ph.D.
Rockford Institute
934 North Main Street
Rockford, IL 61103

Mitchell Carrier
165 Essex Street
Beverly, MA 01915

Paul Castellani, Ph.D.
Local Services Project
Office of MR/DD
44 Holland Ave.
Albany, NY 12229

Addie Comegys
PO Box 491
Wenham, MA 01984

Charlie Diertele
People First Representative
PO Box 7337
Boulder, CO 80306

Mrs. Irene Dixon
Route #1
Box 41
Leonardtown, MD 20695

Gunnar Dywbad, Ph.D.
Professor Emeritus of
Social Welfare
Florence Heller School
Brandeis University
Waltham, MA 02154

Rosemary Dywbad
Florence Heller School
Brandeis University
Waltham, MA 02154

Jean Elder, Ph.D.
Commissioner
Administration on Developmental
Disabilities
Room 336-E
200 Independence Avenue SW
Washington, DC 20201

Susan Epstein
Project SERVE
101 Tremont Street
Boston, MA 02108

JoAnn Gasper
Deputy Asst. Secretary for
Social Services Policy
ASPE/DHHS
200 Independence Avenue SW
Washington, DC 20201

Robert Gettings
Executive Director
National Association of State Mental
Retardation Program Directors
113 Oronoco Street
Alexandria, VA 22314

Sandra Herman, Ph.D.
Research and Evaluation Division
Dept. of Mental Health
Lewis Cass Building
Lansing, MI 48926

Jennifer L. Howse, Ph.D.
Deputy Sec. for Mental Retardation
Dept. of Public Welfare
Health and Welfare Bldg., Room 302
Harrisburg, PA 17120

Ruth Katz
National Association of State Mental
Retardation Program Directors
113 Oronoco
Alexandria, VA 22314

Susan Lamb
6040 Grelot Road #105
Mobile, AL 36609

Dorothy Lipski, Ph.D.
12 James Street
Northport, NY 11768

Lynn McDonald-Wikler, Ph.D.
School of Social Work
Henry Mall
University of Wisconsin
Madison, WI 53706

Susan Mullen
Office of Mental Retardation
Department of Mental Health
160 North Washington Street
Boston, MA 02114

Mike Morris
Comprehensive Development Center
T-214 Fort Missoula
Missoula, MT 59801

Angela Novak, Ph.D.
Wisconsin Dept. of Social Services
Community Options Program
1 West Wilson Street
Madison, WI 53703

Elaine Ostroff
Adaptive Environments Center
Mass. College of Arts
621 Huntington Ave and Evans Way
Boston, MA 02115

Robert Perlman, Ph.D.
Professor Emeritus of
Social Welfare
Brandeis University
125 Lincoln Street
Newton, MA 02161

Teresa Plachetka
c/o Representative Debbie Stabenow
412 Roosevelt Building
State Capitol
Lansing, MI 48909

Margaret Porter
Program Analyst
Dept. of Health and Human Resources
HHH Building (Room 433 F-1)
200 Independence Avenue SW
Washington, DC 20201

Anne Rugg
Research Analyst
Human Services Research Institute
120 Milk Strret (8th Floor)
Boston, MA 02109

Donald Sappern
National Continuity Foundation
253 Riverside Ave.
Westport, CT 06880

Jerry Silverman
ASPE/DHHS
Room 447F
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

James Shorter
Executive Director
State Council on Developmental
Disabilities
1507 21st Street (Room 320)
Sacramento, CA 95816

Kris Slentz, Ph.D.
Center on Human Development
University of Oregon
901 East 18th Street
Eugene, OR 97403

Rebecca Spence
Human Services Research Institute
120 Milk Street (Eighth Floor)
Boston, MA 02109

Warren G. Stambaugh
Virginia State Legislator
Suite 323
2425 Wilson Blvd.
Arlington, VA 22201

Alice Wells
Autism Services Association
36 Pleasant Street
Watertown, MA 02172

Joel West, Ph.D.
Department of Education
Seventh and D Streets, SW
Room 3915, ROB-3
Washington, D.C. 20202

Colleen Wieck, Ph.D.
State Council on Developmental
  Disabilities
101 Capital Square Building
550 Cedar Street
St. Paul, MN 55101

APPENDIX B: DIRECTORY OF 22 FAMILY SUPPORT PROGRAMS

CALIFORNIA

Family Support Services
Department of Developmental Services
1600 Ninth Street
Sacramento, CA 95814

(916) 445-6888

CONNECTICUT

Parent Deinstitutionalization
  Subsidy Aid Pilot Program
Department of Human Resources
110 Bartholomew Avenue
Hartford, CT 06115

(203) 488-3673

FLORIDA

Family Placement Program
Department of Health and
  Rehabilitation Services
Rehabilitation Services Program
1311 Winewood Boulevard (Bldg. 5)
Tallahassee, FL 32301

(904) 488-4257

IDAHO

Developmental Disabilities In-Home
  Financial Assistance Program
Bureau of Developmental Disabilities
Division of Community Rehabilitation
Department of Health and Welfare
450 West State Street
Boise, ID 83720

(208) 334-4181

INDIANA

Family Subsidy and Respite Program
Department of Mental Health
429 N. Pennsylvania Street
Indianapolis, IN 46204

(317) 232-7826

LOUISIANA

Family Subsidy Program
Office of Mental Retardation
Department of Health and Human Resources
721 Government Street
Baton Rouge, LA 70802

(504) 342-6077

MARYLAND

Family Support Services Program
Mental Reardation and Developmental
  Disabilities Administration
Dept of Health and Mental Retardation
201 West Preston Street
Baltimore, MD 21201

(301) 383-3355

MICHIGAN

Family Support/Subsidy Program
Department of Mental Health
Lewis Cass Building (Sixth Floor)
Lansing, MI

(517) 373-2900

MINNESOTA

Mental Retardation Family Subsidy Program
Division of Retardation Services
Department of Public Welfare
Centennial Office Building (Fifth Floor)
St. Paul, MN 55155

(612) 296-2147

MONTANA

Family Training, Support and
  Respite Services Program
Division of Developmental Disabilities
Departmrnt of Social and Rehab. Services
PO Box 4210
Helena, MT 59604

(406) 443-2995

NEBRASKA

Disabled Persons and Family
Support Program
Aged and Disabled Services Unit
Department of Social Services
PO Box 95026
Lincoln, NB 68509

(402) 471-3121

NEVADA

Family Preservation Program
Division of Mental Health and
Mental Retardation
Frontier Plaza (Suite 244)
1937 North Carson Street
Carson City, NV 89710

(702) 885-5943

NEW JERSEY

Home Assistance Program
Division of Mental Retardation
222 South Warren Street
Trenton, NJ 08625

(609) 984-0152

NORTH DAKOTA

Family Subsidy Program
Division of Developmental
Disabilities
Department of Human Services
State Capitol
Bismark, ND 58501

(701) 224-3243

OHIO

Family Resources Services Program
Department of Mental Retardation
and Developmental Disabilities
30 East Broad Street (Room 1220)
Columbus, OH 43215

(614) 466-6670

OREGON

Mental Retardation and Developmental
Disabilities Program Office
2575 Bittern NE
Salem, OR 97310

(503) 378-2429

PENNSYLVANIA

Mental Retardation Family Support
Services Program
Div. of Community Day and Support Programs
Office of Mental Retardation
302 Health and Welfare Building
Harrisburg, PA 17120

(717) 787-5102

RHODE ISLAND

Parent Deinstitutionalization Subsidy
Aid Program
Division of Mental Health, Retardation and
Hospitals
600 New London Avenue
Cranston, RI 02920

(401) 464-3235

SOUTH CAROLINA

Family Care Program
Department of Mental Retardation
PO Box 4706
Columbia, SC 29240

(803) 758-3671

VERMONT

Family Support Services Program
Community Mental Retardation Programs
Department of Mental Health
Center Building
103 South Main Street
Waterbury, VT 05676

(802) 241-2636

WASHINGTON

Home Aid Resources Program
Division of Developmental Disabilities
Department of Social and Health Services
Office Building #2
Mail Stop 42-C
Olympia, WA 98504

(206) 753-4425

WISCONSIN

Family Support Demonstration Project for Families
  with a Child who is Severely Disabled
Developmental Disabilities Office
Department of Health and Social Services
PO Box 7851
Madison, WI 53707

(608) 266-7707

APPENDIX C: DIRECTORY OF FINANCIAL PLANNING AGENCIES

BRIDGE FOUNDATION

The Bridge Foundation
1790 Broadway
New York, NY 10019

(212) 399-0407

FOUNDATION FOR THE HANDICAPPED

Foundation for the Handicapped
1600 West Amory Way
Seattle, WA 98119

(206) 283-4520

GUARDIANSHIP, ADVOCACY AND PROTECTIVE SERVICES (GAPS)

Guardianship, Advocacy and
Protective Services
Oregon Association for Retarded
Citizens
1745 State Street
Salem, OR 97301

(503) 581-2726

INLAND COUNTIES MASTER TRUST

Inland Counties Master Trust
PO Box 2664
San Bernadino, CA 92406

(714) 888-6631

NATIONAL CONTINUITY FOUNDATION

The National Continuity Foundation
co/ Donald Sappern
253 Riverside Avenue
Westport, CT 06880

(203) 226-1288

PACT

Pact
6 North Michigan (Suite 1700)
Chicago, IL 60602

(312) 853-0226

PERMANENT PLANNING

Permanent Planning
co/ Exceptional Persons
2530 University Avenue
Waterloo, IA 50701

(319) 232-6671

PLANNED LIFETIME ASSISTANCE NETWORK

Planned Lifetime Assistance Network
Network (PLAN)
PO Box 323
Charlottesville, VA 22902

(804) 977-9002

SENTRY FUND

Sentry Fund
Kent County Association for
Retarded Citizens
1225-37 Lake Drive, SE
Grand Rapids, MI 49506

(616) 459-3339

STAR SYSTEMS CONSULTATION AND TRAINING

Star Systems Consultation and Training
1011 -70th Avenue
Philadelphia, PA 19126

(215) 549-5440

VIRGINIA BEACH COMMUNITY TRUST

Virginia Beach Community Trust
MR/DD Programs
Pembroke Six (Suite 218)
Virginia Beach, VA 23462

(804) 499-7619